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Solidarity: reflections on an emerging concept in bioethics

Barbara Prainsack and Alena Buyx

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Disclaimer

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Summary

Introduction

1. References to solidarity are currently on the increase in public discourse. In the UK and beyond, during economic crises and in a political climate where many feel that mutual assistance has lost currency, calls for a new and forceful emphasis on the meaning of solidarity are increasingly heard. Such appeals to solidarity are inevitably linked to ideas about how societies function, and about how and where the boundary between individual, familial, communal and societal spheres of responsibilities should be drawn.

2. Policy making that relates to bioethical issues often centres around the relationship between the individual on one side and larger groups or the state on the other, and considers the obligations, rights and claims of those involved in these relationships. Policy making questions in this area in bioethics are becoming more important and more politically recognised. However, this is a relatively recent development that has not been yet been fully explored. Against this background, the Nuffield Council on Bioethics thought that a systematic analysis of the uses of solidarity in recent bioethics writing had the potential to inform bioethical thinking and policy more widely and explicitly and therefore commissioned a report on solidarity in recent bioethics literature. This report was written during a placement Fellowship jointly funded by the Nuffield Foundation and the Arts and Humanities Research Council, with administrative support from the Economics and Social Research Council and some additional funding from the Nuffield Council on Bioethics.

Chapter 1 Solidarity: genesis of a concept

3. While some scholars highlight the origin of the term solidarity in Roman law, others often begin to recount the history of solidarity by referring to the increasing use of the term *solidarité* during the French Revolution. Following a pamphlet titled *Solidarité* in 1842 by Hippolyte Renaud, it was Auguste Comte who in 1875 increased the visibility of solidarity in contexts that were not directly religious or political. He argued that solidarity could be a remedy for the increasing individualisation and atomisation of society, which needed to be subordinated to social concerns and the wellbeing of the collective – a thought resonating with social contract theories of the time. One of the first social theorists to conceptualise the term solidarity explicitly was Emile Durkheim. In his *The Division of Labour in Society* (1893), he developed a distinction between mechanical and organic solidarity, drawing upon the idea of sameness, a shared feeling of those joined together by religious beliefs, lifestyles, training and familial bonds.

4. Christian writing contributed significantly to the development of the concept. The Christian ideal of fraternity is often regarded as the most important precursor of the concept of solidarity. The ideal of assistance between friars in Catholic orders, whose fates were tied to one another in very immediate ways, served as an ideal for how people sharing a particular situation should feel connected to each other and assist each other. This thought became prominent in Christian writing particularly during the emergence of capitalism, when it was felt that radical shifts in the organisation of production and habitation disrupted some of the existing bonds between people, and the need for new forms of mutual alliance and assistance became apparent. Solidarity in Christian writing also emphasised the idea of fellowship between equals. Even if equality did not apply in practice in society or with regards to the access to resources, it pertained to the idea that every human being was worth the same in God's eyes. This notion also applied to people in remote (especially poor) countries. In some Protestant literature, solidarity assumed the role of a religious-moral imperative to assist fellow Christians in their quests for social justice, or more generally, for leading a good life.

5. In Marxist and Leninist theories, solidarity derived from the perception that those who are bound together by occupying the same place in the capitalist mode of production – those who are in the same class – share common interests and should provide mutual assistance to each other. Solidarity was seen initially as applicable exclusively to the working class, however – as demonstrated by the internationalisation of workers' movements throughout the 19th century – national borders were to be disregarded. The need of providing mutual assistance to one's fellow workers also underpinned the beginning of the formation of trade unions in Europe in the second half of the 19th century. In addition, trade unions were destined to help overcome the fragmentation of the working class.

Chapter 2 Recent developments and approaches

6. Since the 20th century, the concept of solidarity has attracted interest mainly from communitarian thinkers. However, it has also played a role within other approaches, such as rational choice or feminist theory. Moreover, it remains an important concept in modern Marxist and Leninist discussions.

7. While in general, communitarianism – understood as an approach that propagates the need of societies to take the collective as a primary point of reference – arguably dates back to the earliest days of political philosophy, it is often seen to have emerged as a reaction to John Rawls' *Theory of Justice* (1971). Communitarianism has been understood to challenge the hierarchy between dominant values in ethics (particularly with respect to autonomy), with community values taking a more prominent role. In general, communitarians are seen to extend the range of values that serve as points of reference in ethical reasoning. Reciprocity, mutuality, citizenry, universality and solidarity, are such points of reference. In sum, the concept of solidarity envisaged by communitarians centres around the preservation of a particular shared understanding of society and its goals, as well as a shared idea of the good life – in short, it is based on a common good. Such a substantive, 'thick' understanding of the good is one of the main tenets of modern communitarianism.

8. Sociologist Michael Hechter is the most prominent scholar in the rational choice tradition to write about solidarity. He sees groupness as the core property of solidarity, yet he endorses a very particular understanding of the term, stemming from his longstanding interest in how to explain individual behaviour. Hechter's approach to solidarity is based upon the assumption that people deliberately form or join groups in order to consume excludable jointly produced goods. Insofar as group members comply with group rules out of a sense of obligation (not fear of coercion), they act out of solidarity. Hechter does not derive any conclusions with regards to substantive political or ethical arguments from his understanding of solidarity; instead, he develops a model with the explicit aim of allowing rational-choice oriented social scientists to operationalise solidarity.

9. Another prominent interpretation of a core meaning of solidarity is to understand it within a contractual framework. Authors in this tradition often suggest that solidarity underpins the concept of the welfare state. There is an ongoing debate, however, around the differentiation between solidarity and other forms of assistance according to whether or not the provision of assistance is based on a contractual relationship. Some authors claim that if someone gives something to someone else – either directly in the form of payment, or indirectly via contributing to transfer payments via paying one's tax – because the receiver has a *right* to the reception of the good or service, the giving is seen as not being based on solidarity. The strongest view on this is that solidarity is never based on contractual duties.

10. Other variants on solidarity include references to the gift relationship (with frequently synonymous uses of solidarity and altruism); reflective solidarity; and agonistic solidarity.

Chapter 3 Solidarity in recent bioethical writing

11. Despite the fact that the frequency of mentions of the term solidarity has recently increased in public discourse, explicit references to the term solidarity are relatively rare in recent bioethical writings compared with other terms such as autonomy, justice, privacy, identity etc. However, solidarity as a concept, an idea, or a value, is much more prominent in bioethical writings than the frequency of explicit uses of the term might have suggested. There is a discrepancy between the number and scope of discussions in which the term solidarity is employed explicitly and those discussions where situations, norms, and dilemmas are associated with solidarity by some authors but not others. With more explicit focus on solidarity and more analysis of what solidarity means and what it can do in bioethical discourse, its rise to prominence can be expected to continue further.

12. Where they exist, explicit references to solidarity appeared mainly in four different contexts within the bioethical literature. These are analysed in detail in the report.

    i. Firstly, in the context of **public health**, where solidarity is regularly discussed as a value capable of justifying the comparably stronger involvement of state authorities in public health;

    ii. Secondly, in the context of **justice and equity of healthcare systems**;

    iii. Thirdly, when it is invoked normatively in connection with providing assistance to poor countries and societies in the context of **global health**; and

    iv. Finally, when it is referred to as a **European, as opposed to an American, value**. This latter point cuts across all other domains: it becomes pertinent when authors contrast European healthcare systems with US healthcare, or when the role of autonomy in bioethics is discussed.

13. All four of these contexts represent relatively young areas of exploration in bioethics. It is no coincidence that solidarity rose to more prominence over the last decades, since this is exactly the time during which the four areas developed from small side-issues in bioethics into full-blown bioethical debates, engaging academics, policy makers and the public in equal measure. All four areas invite invocations of solidarity because they focus on questions beyond the individual, addressing societal issues and the different relationships these play out in, including arguments about the actors in these relationships as well as responsibilities, obligations and claims.

14. Most of those writing about solidarity in bioethics in the four contexts do so with a distinctly positive aim regarding solidarity's importance and use. They call for further attention to solidarity when discussing bioethical questions, or even for its protection against threats such as the increasing individualisation within modern (welfare) states. Others are more critical towards the use of the concept of solidarity, with the main accusation often levelled – not at the concept itself – but at its use in order to justify conduct. Several authors criticise that solidarity is mobilised in a particular context at all, as the term is allegedly too vague for this purpose, or "theoretically unfruitful and even misleading" (Rippe 1998: 357). In addition, some objections to solidarity focus on its alleged substantive content as such and see it as anti-individualistic.

15. There is, on the whole, no coherent way in which the term solidarity is used in bioethics. Most explicit uses of solidarity fall into one of two categories: (i) descriptive: referring to the 'fact' of social cohesion within a particular group; or (ii) prescriptive: calling for more social cohesion within a group. If the meaning of the term is taken to be descriptive, namely as describing an empirical fact – i.e. that particular people are tied together by bonds of mutual assistance, shared goals, and/or other aspects of a situation that they share – then solidarity is a precondition for all social and political life. If the term is used in a prescriptive manner, so that it for example normatively calls for mutual support within a specific group of people, or for more

social cohesion in society as a whole, then the assessment of the value and importance of solidarity takes on a political form. This can lead to a lack of reasoned justification and argument; invoking solidarity sometimes appears to take the place of offering a more careful analysis of, for example, benefits and costs and other relevant factors that should be considered in the justification for a particular course of action or policy.

16. There is great variety regarding the scope of the group that solidarity applies to, ranging from solidarity within a family to solidarity with all people in the world. At the same time, there is very little literature within bioethics that discusses empirically or conceptually how group identities and senses of belonging emerge.

17. The value that solidarity is most frequently associated with or even equated to is social cohesion. Only few contributions (mainly in connection with welfare systems and global health) refer to substantive values that solidarity is seen to support or enact (e.g. global justice; fair distribution of scarce resources).

18. In addition to these main findings, which were drawn from direct reference to the body of works examined, there is also an overarching observation which emerges not only from the sum of bioethics academic publications in the field of bioethics, but also from non-academic sources, and from the verbal input during the workshops in the course of the project. In societies with a high density of formal or informal solidaristic institutions (traditions of volunteering; strong welfare states etc.) solidarity seems to be engrained in society to such a large extent that it does not need to be affirmed by making it explicit. It is only when solidaristic arrangements are seen as being under threat – such as in the case of the NHS in the UK, or of social welfare arrangements in other European countries – that reflections on solidarity and what it means become more visible. Thus, threats to solidarity seem to strengthen attention to solidarity exactly at a time when solidarity itself seems under threat of disappearing. This seems to be the case in public discourse, as well as in policy documents and academic writing.

19. However, if it is true that solidarity becomes most visible when under attack, it is surprising that there are so few explicit mentions overall. With regards to the field of bioethics specifically, the diagnosis that the crises of recent years have increased the currency of solidarity stands in contrast with the overall low visibility of solidarity in recent bioethical writings – at least in terms of explicit references and discussions.

Chapter 4 Related terms

20. One of the difficulties when analysing solidarity is that there are a number of related concepts that in some of the literature are used almost synonymously. This contributes to the perception expressed by some authors that solidarity is a vague term and that it is neither possible to distinguish it from related terms nor to come up with a clear definition of its core meaning. Chapter 4 offers descriptions, in which we try to distinguish some of the features of important related terms from the concept of solidarity.

21. **Responsibility** refers to actors being accountable for an act or an omission of an act. This accountability can be moral, legal, or social (often these dimensions overlap). Responsibility is articulated not only in responsible (moral and accountable) behaviour but also in *expectations* of such behaviour. Furthermore, the notion of responsibility is closely linked to the possibility of consequences that the actor perceives as negative in case she does not act responsibly. The link between responsibility and possible consequences or sanctions is the main difference between responsibility and solidarity. Both can apply to individuals and collectives, but solidarity usually does not necessarily penalise those who are unsolidary (unless solidarity is articulated in contractual or other legal arrangements; or in cases where unsolidary behaviour is penalised by social stigma). In other words, accountability is configured differently in the context of solidarity than it is in the context of responsibility.

22. The term **charity** in Christian theology signified the ability of people to love entities other than themselves – that is, their fellow human beings, but also God – in an absolute way. The love of

others articulated itself in giving and caring, without demanding or expecting anything in return (thus the term 'charitable giving'). Charity always assumes an asymmetric, top-down interaction, where the – overall – more privileged party gives to the – overall – less privileged party. Charity and solidarity are sometimes both used to signify the objective or willingness to accept costs (financial, emotional, or otherwise) that are incurred by improving the situation of others. However, charity is associated with voluntary giving of the richer and more privileged to the poorer and more needing without the latter having any political or legal claims to it. Solidarity, in contrast, is regularly described as taking the form of institutionalising accepted moral claims of groups in need as *de facto* or *de jure* rights. Thus solidarity assumes symmetry in the respect which is relevant (e.g. I recognise the vulnerability of my ill neighbour as potentially my own, because I could also fall ill).

23. Several readings of the term **dignity** exist. First, the Kantian reading, which sees dignity as based on rationality (because humans are capable of reason we have dignity [Würde]); second, the Christian reading, which is based on the assumption that dignity results from all human beings being made in the image of God, and being equal in the eyes of God; and third, the understanding that those who carry a human genome deserve dignity. Alongside solidarity, dignity has been cited as a potentially 'European' value and as one of the notions that should be considered as a meaningful complement to the US-American 'Principlism' such as that developed by Beauchamp and Childress. While dignity could be viewed, depending on its reading, as a potential source of solidarity (I am solidary with you because like me, you have dignity, and in that respect we share sameness), this explicit link has not been put forward in the literature.

24. As a general term, **altruism** typically signifies the opposite of selfishness. In this capacity, it means a concern for the wellbeing of others. In practice, the term altruism is used in a broad way to refer to acts and practices of people to benefit others without: (a) being obliged to do so due to a legal norm; and (b) without receiving, or even expecting, anything in return. Altruism is also sometimes used to denote a worldview that is oriented towards a concern for others, rather than being self-centred. The main difference in the point of gravity between altruism and solidarity is that altruism focuses on specific relationships between individuals, whereas solidarity goes beyond that and entails practices and values that are located at the collective level (policies, welfare state institutions etc.).

25. **Reciprocity** refers to symmetrical arrangements of giving and receiving. While some lexicons define reciprocity as returning in kind what one has received, the notion of symmetry is arguably more helpful: It means that what one gives and one receives is equal in value (not in kind). Reciprocical arrangements can be immediate (i.e. specific; I give and receive at the same time, or in very close succession; and I receive directly from the person whom I give to); or intermediate (i.e. generalised; I receive from somebody else than the person whom I give to, and/or I receive in a time delayed manner). Reciprocity is different from both solidarity and altruism, insofar as altruistic and solidaristic acts do not rely on receiving anything in return (or even do not expect anything in return), while reciprocity does.

26. In the broader sense, the term **social capital** denotes the value of social connections and networks and the ways in which people are invested in communities (by bonds of trust, shared interests or other associations). Like solidarity, social capital "has both an individual and collective aspect" (Putnam 2000: 20). Furthermore, like solidarity, social capital is not beneficial for society by definition. The main difference between social capital and solidarity is the requirement of reciprocity inherent in social capital, which is not the case for solidarity. While in solidaristic arrangements reciprocity is often a result, it is not a condition.

27. **Trust** can be described as a person's reliance on someone or something. It is based on a person's experience and relationship with this other person or entity which renders that latter person predictable to the former person in a relevant respect and at least to some extent. It could be argued that some form of basic trust is a necessary precondition of solidarity. Without

the basic trust in the constitutive entity of solidarity – that is, that there in fact is a community or a group of people I share some common fate or features with – it would be difficult to imagine any solidaristic arrangements. However, this is different from the more concrete and direct trust placed in individuals or institutions mentioned before. In these cases, there are specific expectations that something will happen, or will not happen, whereas the basic trust at play in solidarity is more general: reliance on the fact of shared interests, instead of reliance on particular actions (such as some particular benefits) or on omissions of acts (such as some potential harms).

28. In sum, despite sharing some elements or overlapping to some extent in meaning, solidarity can most of the time be distinguished from these related terms. The remaining overlap, for example, the fact that both charity and solidarity entail the notion of accepting costs to assist others, is not problematic. The terms have different points of gravity. Whenever there is a reason to be unsure about which term applies in a given context, this can be cleared by a careful analysis of the language used, and by striving to be as explicit as possible with regards to the arguments made.

Chapter 5 A new approach to solidarity

29. As highlighted in previous chapters, solidarity is often criticised for being a vague term. It could be argued that such 'vagueness' has benefits, such as a certain level of openness that allows wider ranges of people with different professional and disciplinary backgrounds to contribute to the discussion. However, we believe that such benefits are clearly outweighed by the benefits of a transparent definition of the term involved. In Chapter 5, we therefore set out a new understanding of solidarity and develop a working definition. We do this on the basis of the analysed bioethical literature and other writings laid out in previous chapters.

30. In our understanding, and in its most bare-bone form, solidarity signifies **shared practices reflecting a collective commitment to carry 'costs' (financial, social, emotional or otherwise) to assist others.**

31. It is important to note that solidarity is understood here as a *practice* and not merely as an inner sentiment or an abstract value. As such, it requires actions. Motivations, feelings such as empathy etc. are not sufficient to satisfy this understanding of solidarity, unless they manifest themselves in acts.

32. The term 'costs' is understood to mean a wide range of contributions that groups or individuals make to assist others. It does not exclude scenarios where groups and individuals involved in such solidarity practices *also* benefit from this involvement. Unlike the costs that are carried, such benefits, however – or even the expectation of a benefit – are *not a precondition* for solidarity.

33. Although solidarity is to be understood primarily as a shared practice (or a cluster of such practices) reflecting a collective commitment, simply claiming that such practices exist is unsatisfactory. The working definition therefore consists of three tiers starting with a conceptualisation of how individuals come to engage in practicing solidarity. They stand in a hierarchy of institutionalisation, with the first tier at the interpersonal and most informal, and the third tier at the most formal – legal – level.

34. **Tier 1 Interpersonal level**: The first, 'lowest' tier applies to the level of individuals. At that level, solidarity comprises **manifestations of the willingness to carry costs to assist others with whom a person recognises sameness or similarity in at least one relevant respect**. The recognition of similarity with one (or more) other people in one relevant respect can take many forms: it entails the awareness of being associated, by choice, by 'fate', or other circumstances, with others. For example, I recognise similarity with my fellow air traveller in that we both will miss our connecting flight due to our delayed departure. What counts as similarity *in a relevant* respect is dependent on the context of the practice that I am engaged in: if I sit on an airplane and worry about making it to a meeting on time, then *similarity in a relevant respect* to the

person next to me could pertain to both of us going to the same meeting, both of us making it on time, or both of us missing the connection; the fact that my neighbour is, for example, diabetic is immaterial for my practising solidarity (or not) in this situation, even if I may share this and other characteristics with her as well. However, solidarity will regularly be enacted especially but not exclusively with the most vulnerable in a group. Vulnerability as such can be a factor giving rise to the recognition of sameness: in the acute vulnerability and need of my fellow human being I recognise myself when I have been, or will be, in such acute need. Again, the practical context (time, place, social and economic factors) plays a big role because there are some vulnerabilities that I would never recognise as potentially my own (e.g. the possible vulnerability to be addicted to gambling if I never liked gambling).

35. **Tier 2 Group practices**: In cases in which a particular solidaristic practice at the inter-personal level becomes so normal that it becomes more widely seen as 'good conduct' in a given situation, it can solidify into forms of institutionalisation. This is the case, for example, with self-help groups. On this tier, solidarity can be described as **manifestations of a collective commitment to carry costs to assist others (who are all linked by means of a shared situation or cause)**. This is the second and arguably most prominent tier of solidarity. People who share a situation typically share certain risks or positive goals which emerge out of, or define, that situation. People negotiate ways of conduct in that situation (e.g. how to reduce the risk, to prevent harm or to reach a certain common positive goal). For example, those with a particular disease might support each other, share health information to minimise the negative effects of the disease, and organise events to raise funds for research into the disease. The results of all these activities are common practices from which values or principles emerge that are shared by the members of such groups and communities.

36. **Tier 3 Contractual and legal manifestations**: If these values or principles solidify not only into social norms but manifest themselves in **contractual or other legal norms**, then we have an instance of Tier 3 solidarity, the 'hardest', most fixed, form of solidarity. Examples are welfare state and social welfare arrangements, but also contracts between different private actors and international declarations or treaties. While the lower tiers of solidarity can exist without the higher levels, higher levels do not exist without having been preceded by lower levels. In other words, instances of Tier 3 solidarity have, some time in history, emerged out of Tiers 1 and 2, although the lower tiers might have changed following the institutionalisation into Tier 3. For example, it could be that Tier 3 is more or less intact, while Tiers 1 and 2 have (at least partly) broken away. Some claim this is the case with welfare state arrangements at present. The reverse, however, does not apply: not every practice of solidarity at Tiers 1 or 2 solidifies into the 'higher' tiers, nor is it desirable that all of them do so.

37. Some qualifications apply to solidarity at all levels. First, that solidaristic acts are preceded by the recognition of sameness with another person or group in one relevant respect means that the recognition of sameness is based on an overall symmetrical relationship, not on an overall asymmetrical relationship (such as charitable giving). Secondly, it is crucial to again emphasise that solidarity manifests itself not in the sentiment of empathy. Empathy, or similar sentiments, can of course be involved in solidaristic practices; however, solidarity, according to the definition, takes the form of enactments of the willingness to carry costs to assist others. In this sense, solidarity is embodied and enacted rather than merely 'felt'. Third, the extent of the costs carried is not decisive. Solidarity by our definition includes both enactments of the willingness to assist others which would incur relatively small costs – such as my offering my mobile phone to my fellow air traveller – and those which would incur significant costs, such as donating an organ. Fourth, solidarity is not beneficial for society *by definition*: while practices of solidarity in the context of health and bioethics regularly bring about solutions that are considered beneficial for individuals and/or for public health goals, not all solidaristic practices are considered beneficial by everyone, or even by most of us. Fifth and finally, solidarity does not exclude acts of giving on the basis of contractual relationships in principle. Diagnosing that certain actions are based on contractual or legal obligations does not exclude that they are enactments of solidarity at the same time (as is regularly the case within Tier 3 solidarity).

38. In recent years, many authors have criticised the strong focus on autonomy in bioethics. This raises the question whether solidarity and autonomy are conflicting concepts. We argue that the extent to which they are complementary or competing depends on the way in which individuals and personhood are conceived. For example, if we follow a mainstream liberal tradition and consider the autonomous individual as the central unit of analysis, whose rights must be protected and whose interests the person should be able to follow, this autonomous individual could still feel, and act upon, solidarity with other groups or people. In order to obtain solidarity within a particular collective, one would need to either: (a) chose a collective where the desire for mutual assistance (solidarity) is inscribed in the relationships anyhow (e.g. in many nuclear families), or (b) convince individuals that there is a good reason to act in solidarity with others. In this way, the goal of solidarity is entirely compatible with a focus on individual choice and autonomy, and on liberal rights as overarching values.

39. In an alternative model, individuals are not seen as given and clearly bounded entities, but as people whose identities, interests and preferences emerge out of relations to others. Consequently, solidarity can be seen as something that is an 'innate' need (and characteristic) of people. While we are all the same in the sense that we all are solidary with others, we are different with respect to whom we feel solidarity with, and with regards to, why and how, we act upon it. This has two consequences. First, as in the liberal model, solidarity within a collective can be achieved either by focussing on entities where mutual assistance is inscribed in the relationships between people (e.g. within families or in associations), or people can be convinced that there is a good reason to feel sameness with a particular group and act upon it. Second, and in contrast to the liberal model, because the individual is seen as emerging from the relations in which she is embedded, solidarity is at least of equal importance to individual rights and interests. Neither of the two, communal or individual interest, *a priori* weighs more heavily or overrules the other. This second model is the model we assume in our definition.

40. Our understanding of solidarity bridges the separation between prescriptive and descriptive uses of the term. The working definition, as discussed so far, is descriptive as it helps to determine whether solidarity, or other terms, best describe a certain form or context of social/political interaction. It is, however, prescriptive insofar as it contains substantial statements about how to understand the person; namely, as at least partly shaped by her social relations, including those that pertain to her in her capacity as a citizen. What follows from this is that societal and political arrangements that consider these social relations are typically preferable to arrangements that do not.

41. In the following three chapters, we look at how we can operationalise this idea of solidarity. We apply the working definition to three case studies – biobanks, pandemics, and lifestyle-related diseases, to show how a focus on solidarity might help to re-calibrate existing discussions, shift entrenched debates, and set new agendas for policy making. Due to the nature of this project, our suggestions are merely offered as examples. We hope they can stimulate debate and inspire others to also continue work on this topic.

Chapter 6 Solidarity in practice I: research biobanks

42. The systematic collection of biological samples together with disease and/or other phenotypic information is almost as old as clinical medicine. What made biobanks a greater topic for discussion since the beginning of the new century are: (1) the large scale of collections; (2) the systematic approach to sample and data collection and data generation; and (3) the possibility of automatisation of data collection and comparison, the purpose of which is not clinical diagnosis but research. While traditional small-scale collections (e.g. of tumour tissue in pathology departments of hospitals) continue to exist, recent types of biobanks contain samples and data from hundreds of thousands of participants, and provide many new opportunities for data linkage and data-mining. This latter kind of 'new' biobanks has been seen to pose particular ethical and legal challenges. Most prominent in this context have been concerns in four domains: data protection, confidentiality and privacy; genetic discrimination; ownership and informed consent; and return on investment (including access to findings). These are explored in Chapter 6.

43. In summary, genetic discrimination – as well as data protection and privacy – are still contested, with some scholars arguing that the concepts of privacy and confidentiality sit uneasily with contemporary large-scale biobanking. Issues around ownership have been addressed but not solved; and traditional ideas and practices of informed consent are increasingly being challenged. In addition, the heavy administrative, logistical and financial costs incurred by current (re-)consenting and re-contacting requirements for biobank-based research have been criticised as unduly impeding disease research.

44. Applying our understanding of solidarity, we suggest an approach to research biobanks that entails several elements: (a) a new process for agreeing to research participation in the form of a participation agreement; (b) solidarity-informed perspectives on (re-)consenting and communicating findings to participants; and (c) a conceptual shift towards harm mitigation strategies. New research on existing samples and data in biobanks would be unaffected by this model, which would apply only to new participants signing up to a biobank. The use of existing samples and data in a biobank is governed by specific frameworks nationally and internationally.

45. The suggestion for a new approach to research biobanks is informed by our understanding of solidarity in the following ways. First, and reflecting Tier 1 solidarity, it assumes that people are regularly willing to accept costs (the risk of harm, and the inconvenience of participation) to assist others based on the perception of sameness. In cases of biobank-based research where the risk of harm remains below a certain threshold (thus not in *all* cases of biobank-based research), individuals would sign participation agreements where they express their commitment to a certain research endeavour. This entails that they accept certain potential costs, as well as the scenario of their samples and data being used for purposes other than envisaged originally.

46. Tier 2 solidarity would manifest itself in research biobank governance arrangements which envisage research participants as partners in research to whom the research biobank owes respect, transparency, and veracity. The active contribution of individuals to the research biobank is recognised as based on solidarity; the participant and the research biobank are partners in a research endeavour guided by the shared interest to assist others, rather than merely parties in a legal contract. Hence, organisations and institutions hosting research biobanks are committed to a kind of conduct that renders them worthy of solidarity on the side of research participants. A degree of tier 2 solidarity could be seen to be already inscribed in existing data-sharing arrangements (granting of access to datasets to other researchers), and open access publishing standards.

47. If research biobanks are to be based on Tiers 1 and 2 solidarity, we suggest that data sharing is implemented as such an obligation in all research biobanks governance, making it an expression of Tier 3 solidarity. Moreover, Tier 3 solidarity would be present if the partnership model for research participation found entrance into new ways of thinking about consent in this context.

48. This approach would require a number of specific changes to governance:

    a Solidarity-based research biobanks would have to aim for the overall objective to assist others. Research goals and – therefore data use – might change, but assisting others would have to remain the ultimate end, not, for instance, greatest financial profit. Thus, research biobanks which benefit from solidarity-based participation should put governance structures in place that ensure that research serving pressing health needs is prioritised over research aiming to generate surplus value.

    b With regards to recruitment, participants would sign an agreement to participate which would not be focussed on specific informed consent, but rather on veracity. Participants would be informed in detail about the mission of a particular research biobank, its funding and

governance structures, and what it hopes to achieve. The initial disclosure would also have to include an explanation that research objectives might change and data may be used to serve research that cannot yet be envisaged, and that appropriate research ethics approval will be obtained wherever laws and regulations require this. The disclosure statement would also have to include a list of risks and benefits insofar as they can currently be foreseen, with an explicit note that this list may not be exhaustive.

c As for re-contacting and communicating of results, for solidarity-based research biobanks it would be acceptable to consider costs of re-contacting participants and to refrain from contacting individuals about information that has no direct individual utility. Furthermore, participants who are interested in seeing data and information generated by the biobank should be expected to take the initiative of accessing the data via online platforms or other repositories.

d Finally, in order to enable cost-effective and non-bureaucratic mitigation of harms, solidarity-based research biobanks would have to establish dedicated funds for compensation of individuals affected by harm (such as demonstrable cases of discrimination by employers or insurance companies).

Chapter 7 Solidarity in practice II: pandemics and global health – the case of 'swine flu'

49. The word 'pandemic' signifies an infectious disease actually or potentially diffusing on a global scale. The concrete focus of analysis in this chapter is the swine flu pandemic of 2009/10. We chose this example because it shows the complexities involved in collective and individual decision making in a context of high risks and high levels of uncertainty.

50. The so-called swine flu H1N1 virus became notorious because of the pandemic that it caused in 2009. The World Health Organization (WHO) advised countries to implement their pandemic plans in August 2009. In August 2010, when the WHO declared the pandemic to have ended, the virus was believed to have caused at least 18,000 deaths. Because of the relatively small proportion of the 2009-10 swine flu pandemic compared to the scale that had been expected, national health authorities as well as the WHO attracted criticism from the media for allegedly having caused unnecessary panic and disruption; moreover, it was argued that the panic that was created served the vested interests of those who wanted to sell drugs, and to justify the WHO's budget

51. The alleged 'panic' expressed itself in proposals to close airports and schools, in the introduction of border screening measures, and in initiatives and recommendations by many national health authorities for people in 'vulnerable groups' to be vaccinated. In the UK, pregnant women, those living with immunosuppression or those on renal dialysis, and people in the seasonal flu vaccine at-risk groups were contacted by their GPs and offered vaccination. The vaccine used for this purpose was highly controversial in many countries as some claimed it caused a disease affecting the nervous system, the Guillain-Barre Syndrome (GBS). Fears were expressed that more people could die from the vaccine than from the flu itself. The use of the vaccine for children was particularly controversial as the substance had not been tried on children. In addition to criticism directed towards health authorities for allegedly creating a flu panic, the media was criticised for creating a vaccination panic.

52. Compared with the previous case of biobanks, the stakes involved in the context of pandemics are different, because risks and costs are distributed very unevenly. Simultaneously, the potential costs incurred by containing pandemics are typically not limited to relatively small costs (comparable with the costs carried by participants in research biobanks) but they can be very considerable for some people. This affects the perception of sameness in the relevant sense and consequently, the willingness to carry costs to assist others. For those at high risk, no costs incurred by measures to contain the pandemics may be too high; yet for those at relatively low risk, actions that impose additional risks on them (risk of falling ill from vaccination; risk of losing

out on income or opportunities due to the impossibility of getting to work or travel) may already be too high a cost.

53. We believe that because the recognition of sameness with others plays such an important role in fostering solidarity at the level of the individual, it is unreasonable to expect that entire populations – where risks and stakes are very unevenly distributed – will accept the costs of containing pandemics *out of solidarity with each other*. Tier 1 solidarity is too weak to support the higher levels of solidarity required for this; unlike with research biobanks, there are few existing instances of 'voluntary' practices and commitments at individual and community levels in the domain of pandemics (Tier 2 solidarity). Although there may be communities of risk comprising those who face particularly high risks in face of a pandemic, the actual or potential costs of preventing these risks affect the entire population, the members of which may not all feel solidary with each other. Hence, policies and legal norms to prevent and contain pandemics would not be expressions of Tier 3 solidarity, but rather of top-down state power, raising issues of paternalism and illegitimate state force in democratic societies.

54. This is not to say that people would not, or should not, accept the costs incurred by containing a pandemic; the justification for the authority of state actors to enforce the necessary measures, however, will need to employ a different justification other than invocations of solidarity. At the interpersonal level, thus, pandemics represent a case where the potential of mobilising solidarity to obtain ends that are desirable in a public health context, is limited. We explore three examples in the chapter to argue this point: vaccination; triage; and surveillance and restriction of movement.

55. In sum, state-enforced measures of public health, such as vaccination, cannot be argued only on the basis of solidarity. Such measures need a different kind of justification, for example the duties of the state to protect vulnerable groups in a stewardship state model. Similarly, triage cannot be justified by referring to solidarity. The most plausible justification is, yet again, that by imposing standards for triage, state authorities fulfil their duty to protect the most vulnerable. However, some measures that restrict movement, such as school closures, can be assumed to play out at the level of interpersonal solidarity and involve sufficient degrees of similarity between actors; they can be argued with reference to solidarity.

56. There is some evidence that social media tools, such as Twitter or Facebook, can strengthen the perception of sameness between people with whom they would not have come into contact otherwise. Their recent and increasing use in times of crises can also be seen as an emerging solidarity practice. Social media could be used in pandemics, for example, to track the spread of diseases, to disseminate and support public health measures, and to create networks for the collation and analysis of information.

57. With regards to the relationship between countries in case of an impending pandemic, our understanding of solidarity can be invoked. In the context of pandemics, in a time of globalised travel, all countries share the risk of a pandemic spreading and involving their territory. Even though countries do not have feelings like individual persons, they are similarly interconnected. Moreover, pandemics do not care about national borders. Despite significant differences in infrastructure, wealth and the potential need for resources, countries are therefore similar in a relevant sense. Thus, although they are not individuals or persons, Tier 1 solidarity can be applied to state actors.

58. The sameness should be emphasised when global cooperation is negotiated in case of an emerging pandemic; in other words, the implicit references to solidarity present in many writings by global actors such as the WHO should be made explicit. In many instances, especially when the incurred costs are relatively low (e.g. sharing of surveillance data; informing other countries of disease outbreaks so that they can get prepared), and/or the benefits are very high (e.g. increasing approval rates of an unpopular government), countries already enact or will enact solidarity with one another; the last swine flu epidemic provides us with many examples of such

collaboration. Yet in situations where the immediate benefits are expected to be low and the incurred costs are likely to be high, achieving mutual assistance among countries remains difficult. Invoking solidarity in the way we have demonstrated here, and using this understanding of solidarity to argue for particular international measures, could go some way to support responding to this challenge.

Chapter 8 Solidarity in practice III: lifestyle-related diseases

59. There is no universally accepted definition of the term lifestyle-related diseases, yet it is common to subsume under this term diseases that are increasingly prevalent in wealthy nations with affluent lifestyles (they are sometimes referred to as 'diseases of civilisation'). In this tradition, 'lifestyle' refers to behaviour associated with affluence that is detrimental to our health, such as sedentary work and leisure activities (e.g. no physical labour, being a 'couch potato'), high intake of sugary, cholesterol-rich and fatty foods, and high levels of consumption of alcohol. These are seen to have particularly high risks for illness. Diseases commonly associated with such lifestyles are, for example, many types of cancer, asthma, type 2 diabetes, obesity, osteoporosis, and sometimes also depression and certain autoimmune diseases.

60. Resources are becoming increasingly scarce in all advanced healthcare systems. This is due to many factors, amongst these the epidemiological transition towards longevity, continuing medical progress and increasing demand for health care. Consequently, questions of how to allocate healthcare resources fairly and efficiently have been discussed extensively over the last two decades. A substantial part of this debate is devoted to whether individual responsibility should be used as a criterion to allocate – or ration – healthcare resources.

61. Those who suggest individual responsibility as a rationing criterion in healthcare almost always refer to lifestyle-related disease in some way. For example, some argue that the treatment of conditions based on lifestyle and health behaviour should be excluded from publicly funded healthcare or insurance plans, and there are policies in existence already that use financial disincentives to deter unhealthy lifestyles.

62. Using individual responsibility and the concept of lifestyle-related diseases in order to exclude patients from free or all publicly funded healthcare, and to reduce insurance coverage based on health behaviour, or levy fines, is based – whether explicitly or implicitly – on risk classification and risk stratification. No matter which concept of lifestyle is chosen, the exclusion is based on the assumption that those excluded have a higher risk of contracting a particular illness (e.g. diabetes type 2 in an obese person), or an overall higher risk of illness. This higher risk is then often linked to cost, meaning that some people with a particular lifestyle incur higher costs for the system than others.

63. We are currently witnessing a widening of the range of scenarios and situations for which people are seen as (at least partly) responsible. The process of rendering individuals responsible for their health has been extended to include those who have known family histories of diseases and refrain from taking additional precautions; those who forego susceptibility testing or other predictive testing which is available to them, and sometimes even those who do not take active steps towards learning more about their individual risks. This process has been called 'responsibilisation'.

64. In general, the risk of falling ill or having an accident is recognised as a shared vulnerability amongst all people. However, with regards to illness that is perceived to have been brought on by freely chosen behaviour, a solidarity-based argument is increasingly made: Our personal understandings of who we are connected with (in the sense of recognising similarity in a relevant respect) shape our judgments of what situations people should be held accountable for. Those who display unhealthy lifestyles are perceived as responsible for their ill health and as literally in a different 'category' from those who care about protecting their health. Sameness in a relevant sense, necessary for Tier 1 and consequently all higher levels of solidarity, is therefore denied. Thus, it is perceived to be warranted to exclude those who engage in unhealthy behaviour from

solidaristic practices that play out on a higher level of institutionalisation (Tier 3): for example, from publicly funded healthcare, or from (public or private) health insurance.

65. However, the notion of responsibility in connection with lifestyle 'choice' is a moving target: it is very difficult to determine a clear causal link between behaviour and illness on an individual level, as most lifestyle-related diseases are caused by multiple factors. Moreover, it is impossible to draw a clear line of separation between situations that people have chosen deliberately and situations that 'fate' or other factors have imposed on people's lives. Moreover, focussing population stratification on risks in one context inevitably disregards risks in other contexts which may not even be visible or determinable.

66. For these reasons, healthcare systems should refrain from taking into consideration factors of risk stratification and individual responsibility for health problems and conditions. Because publicly funded healthcare systems comprise large numbers of people, lifestyle-related risks to health are likely to be balanced out by other risks that cannot be rendered visible or determinable by looking at lifestyle (choices). The lifestyle concept and the idea of personal responsibility for health, if used to claim a violation of solidarity and to deny resources, constitute an arbitrary choice amongst a myriad of risks that affect health, including many social and environmental factors entirely out of the individual's control.

67. A solidarity-based approach would instead mandate that access to healthcare should be granted on the basis of need, as need is a category in which sameness in the relevant sense is easier to see than in lifestyle risk stratification. In order to preserve a solidarity-based healthcare system, it would be necessary to generate cost savings. These should come from administrative instead of frontline services. In addition, it would be important to reverse the trend of individual exceptions to general rules of allocating care (such as prescriptions on patient request). Sacrificing such individual requests should be seen as an enactment of solidarity – carrying some costs to assist others.

68. Moreover, a higher appreciation of the importance of preventive and public health measures, both when allocating resources and in public perception and understanding, would be desirable. For this, there needs to be a shift in public discourse from individual responsibility for health towards mutual assistance in health. A stronger emphasis on similarities and shared commitments would for example involve a focus on public health, due to its inherent reference to collective risk- and benefit sharing. Stories about single individuals saved by miraculous high-tech medicine are typically more interesting to the media; nevertheless, positive narratives about preventive medicine and public health can be told as well. Social media can be particularly powerful in this context. In addition, many open science and participatory health initiatives provide exciting examples of enacted solidarity on the side of its participants, who volunteer time and efforts to collaborate on developing innovative ways to improve health. The potential of such initiatives, which have so far been below the radar of many funding agencies and health authorities, should be utilised and supported.

69. Finally, it would be preferable to call for active and healthy lifestyles in a positive way, as joyful ways of living. And many people may respond positively to the argument that more active lifestyles are one factor that helps support the shared commitment to assisting each other via a public health care system.

Introduction

1 Why solidarity?

1. Solidarity is an elusive concept. Compared with how relevant many scholars consider it for the functioning of society, relatively few books and papers are dedicated to this concept explicitly; moreover, many of us struggle to define it. These two issues are connected. Some of the most fundamental concepts in our lives, such as health, love or happiness, suffer from similar problems of definition. Because they matter to everyone, they must be open enough to accommodate a large range of experiences, feelings, and practices; yet at the same time they need to be specific and firm enough, as concepts, to serve as points of reference to justify or explain actions.

2. Nonetheless, references to solidarity are on the increase in public discourse. In the UK and beyond, during economic crises and in a political climate where many feel that mutual assistance has lost currency, calls for a new and forceful emphasis on the meaning of solidarity are increasingly heard. The 'Big Society' idea, for example, claims to be one variant of this. It suggests "helping people to come together to improve their own lives. [The Big Society] is about putting more power in people's hands."[1] It propagates that people help each other and thus transcend the border between their own needs and interests and the needs and interests of others. At the same time as the Big Society concept promises to foster one version of solidarity – that which it derives from (neo)liberal political theory – it can be seen to turn against another, namely the understanding that due to its fundamental importance in our society, solidarity must not depend on the will of some to help others, but it must articulate itself in concrete enforceable rights. This example shows that the ways in which notions of solidarity are employed are inevitably linked to ideas about how societies function, and about how and where the boundary between individual, familial, communal, and societal spheres of responsibilities should be drawn. It also shows that different understandings of the concept of solidarity result in very different applications in policy.

3. Against this backdrop, the Nuffield Council on Bioethics (NCoB) judged an inquiry into the various uses of solidarity to be both relevant and timely – particularly so in the field of bioethics. Policymaking that relates to bioethical issues often centres around the relationship between the individual on one side and larger groups or the state on the other, and the obligations, rights and claims of those involved in these relationships. Policymaking questions in this area in bioethics are becoming more important and more politically recognised. However, this is a relatively recent development that has not yet been fully explored. NCoB thought that a systematic analysis of the uses of solidarity in recent bioethics writing had the potential to inform bioethical thinking and policy more widely and explicitly, and therefore commissioned this work to be done during a placement Fellowship.

2 Working methodology

4. This report was commissioned by the NCoB and jointly funded by the Nuffield Foundation, the Arts and Humanities Research Council and the NCoB. It differs from other work published by NCoB: firstly, it is not a report *by* NCoB. While NCoB members have lent the work their expertise, for example, in giving comments and providing important input during workshops, the text of this report has not been agreed and adopted by the whole NCoB in the way its other reports are. All opinions expressed in the text are those of the individual authors and should be taken neither as statements of the NCoB, nor as statements of the other funders – the Nuffield Foundation and the Arts and Humanities Research Council. Secondly, unlike NCoB reports,

[1] Cabinet Office (2011) Big Society. http://www.cabinetoffice.gov.uk/content/big-society-overview.

which are prepared over about 18 months with the support of an expert Working Party, this has been the work of two individuals (albeit with help that is gratefully acknowledged) over the course of six months. Therefore, both scope and depth of the analysis are necessarily different from what a NCoB report would provide.

5. The findings of this report rest upon two main pillars. First, between February and May 2011, a systematic literature study was carried out in two phases. Phase 1 involved the electronic search for all publications with the term 'solidarity' in its title, key words, or – in case of journal articles – in the abstract. No additional filter was applied. The search tools *Scopus* and *Google Scholar* were the primary tools used for the search. The 1,000 most recent works[2] resulting from this search were examined, which involved the reading of the abstract in cases of journal articles, or book cover texts and/or tables of content in cases of books. Only those works which either (1) pertained to solidarity in bioethics and/or public health ethics; or (2) said something substantial about solidarity, either conceptually or empirically (or both) were retained for detailed analysis.[3] Furthermore, in order not to miss seminal works on the topic of solidarity published before the particular period of study, the search tool *Scopus* was used to identify the 100 most cited articles containing the term 'solidarity' in its title, key words, or abstract, irrespective of when they were published. All of these were examined, and those which met one or both of the aforementioned criteria were retained for analysis. Phase 2 of the literature analysis involved a targeted search for articles or books containing both the term 'solidarity' and 'bioethics' in their title, abstract, or keyword, again between the years 2005 and (2 February) 2011. This search yielded 51 results, all of which were included in the analysis. In addition, books and articles which were discussed or referenced in articles and books obtained from phase 1 were included in the analysis in phase 2.

6. The second pillar of this reports are the insights obtained from two workshop held at the Nuffield Council on Bioethics in spring and summer 2011. The first one, on 13 May 2011, comprised a number of experts who held a roundtable discussion to discuss common uses of solidarity in bioethics and to discuss a first draft of our working definition. The second workshop, held on 7 July 2011, served to refine our working definition and to discuss drafts of the three case studies. A list of participants in both workshops can be found in the appendix.

3 Scope and structure of the report

7. The subject of this inquiry is such that it could have occupied a much longer period than six months and could easily fill a much larger volume. It is therefore important to stress that this report does not claim to provide a fully comprehensive discussion of all bioethical writings on solidarity. In many areas, we provide an overview of developments, leaving others to fill the gaps we left on our way. Nor do we seek to provide a definite answer to the question of what solidarity means and how it should be employed in bioethical policy making. On the contrary, whilst we hope to have provided some clarification and a first step on the way to a more systematic use of the term solidarity, our main goal is to open up a debate and map out an arena for others to discuss solidarity in bioethics.

8. The first part of this report is largely descriptive and devoted to an examination of solidarity based on some historical material and a systematic analysis of recent bioethics writings. In the first chapter, we briefly describe the genesis of the concept of solidarity, aiming to set the scene and to provide some background on the history of the term which helps to understand the variety of current uses (Chapter 1). We then give an overview of some prominent, more recent uses of the term in fields such as political philosophy or sociology. Whilst this overview has to

[2] These reached back to 2009. It was assumed that older works on the topic of solidarity, if they were influential, would be mentioned in the 1,000 most recent works. Pertinent works mentioned in these articles or books were obtained and included in the analysis in phase 2.

[3] The majority of the publications that were not considered for closer considerations were papers and books which included the use of the term solidarity in a marginal and merely programmatic manner, e.g. to argue a wider societal relevance of their work without saying anything substantial about solidarity, or where it appeared in the title or abstract apparently to help delineate the topical field of the work without being taken up in the text.

be short and thus necessarily incomplete in this report, attempting an analysis of solidarity in bioethical writing without being aware of at least the main applications of the concept in other fields would miss important context and background; in fact, some authors work both in bioethics and in related fields. Moreover, since we develop a new working definition of the term that is potentially applicable to many fields, knowledge of its main uses outside of bioethics is vital (Chapter 2). In Chapter 3, we examine the various ways in which solidarity has been employed in bioethical writings and discussions in the last two decades. We explore the main arguments brought forward mainly in four areas: solidarity and public health; solidarity and justice in healthcare systems, solidarity and global health; and solidarity as a European value. We then look at some of the criticisms of the term, and we draw some conclusions from our analysis. Finally, Chapter 4 provides some analysis of related terms such as altruism, charity or reciprocity that feature in some of the writings on solidarity we examined. These terms are sometimes used synonymously with solidarity, which can lead both to misunderstandings and to the impression that solidarity is an exceedingly vague term.

9. In the second part of the report we set out some of our own thinking. Based on the analysis of the literature in the first part, in Chapter 5 we develop a new approach to understanding the term solidarity, with the aim of enhancing its ability to contribute to bioethical thought in a constructive manner, and to help facilitate a more effective application of the term in policymaking. Finally, we apply this new understanding to three areas of bioethical thinking and policy making, namely, research biobanks (Chapter 6), pandemics (Chapter 7) and life style diseases (Chapter 8). We introduce some basic information on the debates in these fields. We then showcase some of the consequences our understanding of solidarity would have in the real world of policy making and governance. Due to the nature of this project, these and any suggestions we develop are merely offered as examples. We hope they can stimulate debate and inspire others to also continue to work on solidarity and its application in bioethics and policy making.

Chapter 1

Solidarity: genesis of a concept

Chapter 1 – Solidarity: genesis of a concept

1.1 Introduction

1.1 While the focus of this report is on issues relevant to contemporary bioethics, taking a brief look at the historical and political legacy of the term 'solidarity' is helpful in contextualising its use in bioethical writings and discussions today – after all, the history of the term stretches back for centuries and underwent several important, both parallel and successive, stages that continue to inform some of the connotations of the concept today.

1.2 The following is a brief overview that attempts to broadly show some main lines of development of the term solidarity. It is neither comprehensive nor very detailed, as the aim is mainly to provide some historical background for the following analysis of contemporary literature. We also do not cover the ontogenesis of the concept of solidarity outside of Europe and North America. This has to do with the limitation of the sources that were considered to English language literature, but also with the inherent assumptions in the concept of solidarity as such. As Bayertz (1999: 3) points out, etymologically the term solidarity stems from the Roman law concept of *in solidum*, which signified that a contract was joint between two or several creditors or debtors (the term is still in use in civil law today. See also Buyx 2008: 872). This early use of a notion of solidarity presupposes a society which is seen as made up of independent autonomous individuals, whose fate can then be joined, by means of legal (or other) instruments, for a certain purpose and for a particular context. Furthermore, the prominent mobilisation of the notion of *solidarité* in France during the revolutionary period always connoted a strong emphasis on personhood and persons conceived as, if not fully autonomous, then at least as singular.[4] Citizens were called upon to overcome their singularity and stand by others who were neither (part of) them, nor *inseparably* linked to them in their needs and interests. This is fundamentally different from conceptualisations of personhood in other world regions, such as in South East Asia, where some religious traditions do not conceive of persons as singular, or not even as fixed (e.g. Stonington & Ratanakul 2006). For example, the primary Confucian moral obligation always to act so as to contribute to the harmony and balance of one's social context treats the social rather than the person as primary (see e.g. Ruiping 1999; Kasulis et al. 1993). Thus, by default, this report will largely draw upon the genesis of solidarity in European history and politics, and in North American philosophy.

1.2 Early beginnings: classic social theory

1.3 While some scholars (Bayertz 1999, Metz 1999) highlight the origin of the term solidarity in Roman law, other writers often begin to recount the history of solidarity by referring to the increasing use and currency of the term *solidarité* during the French Revolution (e.g. Scholz 2008: 28-32). As Sternø (2005) points out, while the concept of *solidarité* had initially been understood as a legal term – and found entrance in Napoleon's *Code Civil* in 1804 – its meaning and use were extended into the political realm by the revolutionary leaders of the late 18th century. This transition was concealed partly by the fact that the banner under which solidarity migrated into the political realm was not *solidarité* but *fraternité* – brotherhood – which became one of the three key principles of the revolution. First applied to the bonds between revolutionaries, Sternø (2005: 27) notes, "[f]raternity or brotherhood came to denote a feeling of

[4] The large extent to which contemporary European and North American societies hinge on the conception of personhood as singular becomes apparent when we look at the dearth of movies and novels dealing with the topic of human reproductive cloning, and also at the experiences of many identical twins, who report that many people react strangely, if not hostile, to them. This is the case because the idea of human cloning (having the same DNA), and also the concept of twinship (having the same DNA and/or going through life together) challenge the assumption that persons are always primarily singular. Some twins – and, in much of our public imagery, also human clones upset the dominant way in which social and political space is structured by *being singular and dual at the same time* (Battaglia 1995; Prainsack & Spector 2006).

political community and the wish to emphasise what was held in common". This feeling of political community was soon extended to larger groups for which the revolutionaries claimed to speak.

1.4 In 1842, Hippolyte Renaud published a pamphlet titled *Solidarité*, in which he criticised the allegedly myopic and particularistic manner in which exponents of opposing ideologies posed their arguments. He argued that they were overlooking that many of their goals were in fact aligned, and that all humans were connected in their pursuit of wellbeing. Renaud's book helped to spread the concept of solidarity beyond the borders of France, especially into Germany and England, where it was taken up by socialist movements.

1.5 It was the book *System of Positive Polity* (1875 [1851]) of Auguste Comte, often referred to as the 'father of sociology', which increased the visibility of solidarity in contexts that were not immediately religious or political. Comte's use of the term was very strongly prescriptive: for him, solidarity could be a remedy for the increasing individualisation and atomisation of society, which was detrimental to social concerns and the wellbeing of the collective.

1.6 This approach resonates with social contract theories of the 17th and 18th century, of which Thomas Hobbes (1651), John Locke (1689), and Jean-Jacques Rousseau (1762) are the most prominent representatives. Their approaches vary greatly with regards to how they regard the 'nature' of human beings – which ranges from Hobbes' famous assessment that humans are 'wolves' to their fellow humans to Rousseau's assumption that human beings would all live in peace with one another had private property not been invented. What these approaches share in common, however, is that they justify the need for governmental authority (symbolised by Hobbes' image of the Leviathan, the mighty yet inevitably necessary giant). Because of the impossibility for individual people to lead safe and fulfilled lives outside of organised social systems (in which basic infrastructures are protected by means of governmental authority), people are assumed to have agreed to waive their 'natural' freedom to do what they want and to submit under the rule of an authority, which gives them civil freedom in return.[5]

1.7 Solidarity is crucial in this respect: Although they seldom refer to this term explicitly, social contract theorists treat solidarity as an empirical fact and a positive goal at the same time. Solidarity is presupposed to be an empirical fact insofar as it is assumed (and observed) that people prefer lives as part of social collectives over lives as lonesome fighters. Thus, the existence of emotional and economic bonds between human beings is seen as inherent in human nature.[6] At the same time, solidarity is a positive goal insofar as the political and social collectives – organised in the form of territorial states – that social contract theories seek to justify, require the willingness of people to associate themselves with a much larger group of people than those whom they knew in person.[7] Social contract theories *argue* the need for institutionalised mutual assistance because apparently their proponents believed it could not be *presumed*.

1.8 Despite the considerable role that solidarity plays in social contract theories, one of the first social theorists to devote significant attention to the term solidarity explicitly was Emile Durkheim. Durkheim made a considerable contribution to the conceptualisation of solidarity in

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5 The assent of people to submit themselves under the rule of authority is to be understood as a legal and political fiction, not a claim to historical truth.

6 The notion that emotional and economic bonds are inherent in human nature is of course reflected in earlier philosophical writings, such as Aristotle's description of humans as "political animals". "Political" here does not refer to politics in the contemporary, narrower understanding of the term, but to the social sphere in the broadest sense (Aristotle, *Politics*; see also Yack 1993).

7 Anderson's (1991) work on 'imagined communities' is concerned with a similar issue, although Anderson does not utilise the notion of solidarity in a prominent way: Why, and how, do people feel connected to others whom they do not personally know? Anderson's approach to tackling the question focuses on the role of texts, which – catalysed by the emergence of the printing press – enabled people to conceive of a connection to others who existed simultaneously to them in other geographical places, and who shared important characteristics with them.

sociological terms. His distinction between mechanical and organic solidarity, which he developed in *The Division of Labour in Society* (1893), has become one of the standard points of reference in social and political thought on this topic. People in early societies, prior to the era of division of labour, Durkheim argued, were bound together by the feeling of sameness; they did the same work, were part of the same family, or fought against the same natural threats. This situation he termed 'mechanical solidarity'. The increasing specialisation of work, however, which went hand-in-hand with changes in how and where people lived, altered the nature of ties between people. Durkheim referred to this latter situation as 'organic solidarity', to signify that people were bonded together by being dependent on each other. It could no longer be taken for granted that people who worked or lived together felt *sameness* with each other in many different respects; they often had different trainings, religious beliefs, lifestyles and familial bonds. The production cycle – in which those who sell a good depend on those who manufacture it, who in turn depend on both those who pay them and those who provide the natural resources – became the new source of bonds between people. Weber's (1964 [1022]) notions of affective communal (*gemeinschaftliche*) vs. rationally motivated associative (*gesellschaftliche*) bonds between humans is closely related to Durkheim's distinction (see also Tönnies' *Community and Society,* 1887).

1.3 Solidarity in Christian theory, politics and ethics

1.9 Another important field contributing to the development of solidaristic ideas and uses of the term was Christian writing. Sternø (2005: 26), for example, considers the Christian ideal of fraternity as the most important precursor of the concept of solidarity (similarly Brunkhorst 2007). Although the articulation and enactment of the fraternity ideal in monasteries is of course much older, it was in fact the emergence of capitalism and liberalism which suggested that the value of mutual assistance could bridge the gap between individual rights and liberties on the one hand and the goal of social cohesion and community on the other (Sternø 2005). In other words, due to radical shifts in the organisation of production and habitation taking place during the rise of modernity, which disrupted some of the existing bonds between people (families, village communities etc.), the need for new forms of mutual alliance and assistance became apparent. In this context the ideal of assistance between friars in Catholic orders, whose fates were tied to one another in very immediate ways, served as an ideal for how people *sharing a particular situation* should feel connected to each other, and assist each other. This sense of solidarity had a different meaning and purpose than the Christian concept of *charity* from the start. While charity, as Metz (1999: 199) puts it, was 'the expression of a moral relationship voluntarily entered into by the rich towards the poor', solidarity denoted the idea of fellowship between equals. Even if equality did not apply in practice in society or with regards to the access to resources, it pertained to the idea that every human being was worth the same in God's eyes, and this notion of equality in dignity was seen as more fundamental than others (see also Häyry 2004; Magill & Trotter 2001).[8] For more discussion on the related concepts of dignity and charity and their differences to solidarity, see Chapter 4.

1.10 Within Christian dogma, solidarity assumes special meaning through the sacrifice of Christ for the people. In a Christian version of the *in solidum* idea in Roman law, where people could be jointly liable in contractual relationships with others, Jesus is seen to have 'settled the debt' of the guilt of humans by dying for them. In this sense, through incarnation, God enacts solidarity with humans, and solidarity with people is always also solidarity with God (and vice versa; for a

[8] To bring an example from more recent history, after Hurricane Katrina, which caused deaths and devastation in large parts of the south east of the US in 2005, volunteer organisations chose the phrase 'Solidarity, not charity' as a motto for their work. Reverend Michael Tino of the Unitarian Universalist Fellowship of Northern Westchester, who was part of the volunteers' movement, reflected on the meaning of this motto in a short piece in which he defined charity as helping from a distance, whereas he understood solidarity as standing by someone. Moreover, he recalls a meeting with other volunteers, where "what we talked about was the difference between doing something *for* another person because *you* think it's the right thing to do and doing something *with* another person because *they* have asked for your help. It's the difference between acting out of pity and acting out of compassion" (Tino 2009: 2; original emphases). This clearly illustrates the Christian ideal of solidarity as a fellowship between equals, where one provides assistance to the other out of recognition that every human being's life is of the same worth and dignity.

Catholic expression of this, see e.g. *Encyclica sollicitudo rei socialis* [On Social Concern] by John Paul II 1987).

1.11 There are nuances to how solidarity worked within Christian traditions. Within Protestantism, Lutheran and Calvinist groups differed with regards to how interpretations of solidarity could play out in relation to religious doctrine. While the latter had the clear mission to make the domain of worldly affairs to conform with the rule of God – from which followed the right to resist rulers and rules that were incompatible with religious values – Lutherans were slower in taking up explicitly political agendas due to Luther's so-called 'Two Kingdom' doctrine, which assumed a clear separation between the domains of God and worldly power.[9] This led to a situation where interpretations of solidarity which were seen as critical of the *legitimate* rule of worldly authority sat squarely against religious doctrine. However, the Two Kingdom doctrine also considered people exempt from the obligation to obey laws if they contradicted scripture, personal conscience, or the laws of the land (Sternø 2005: 77). In these cases worldly rule was not considered legitimate. This opened up the possibility for wider discussions of social justice, the fellowship of all beings created in the image of God, and assistance to the needy in all world regions, *within* the realm of religion. In other words, solidarity assumed the role of a religious-moral imperative to assist fellow Christians in their quests for social justice, or more generally, for leading a good life.

1.12 Sternø (2005: 74) understands the Catholic notion of solidarity as the 'the broadest and the most inclusive sort'. It has strong roots in Thomas Aquinas' work stressing community between all human beings, and aims at including everyone, across economic, territorial, and even religious boundaries. The latter is the case because the Catholic version of solidarity extends to people in poorer nations, regardless of their religious affiliation (at the same time, Catholicism has a long history of seeking to bring people in these poorer nations to Catholicism. This, however, does not detract from the Catholic notion of solidarity morally obliging people to help those in need, irrespective of their religious beliefs).

1.13 Although solidarity had always played a role in Christian dogma in general and Catholic social doctrine in particular, solidarity received increasing attention within Christian teachings in reaction to the importance of solidarity as a core value in socialist movements.[10]

1.4 Solidarity in socialist theories and politics

1.14 The important role of solidarity in socialist theories and politics is inseparably linked with continental welfare states. While the latter will be discussed in more detail below (see Cahpters 3 and 8), this section seeks to provide a concise overview of the origins of the use of solidarity in socialist thought, politics and traditions.

Marxism and Leninism

1.15 In Marxist and Leninist theories, solidarity derives from the perception that those who are bound together by occupying the same place in the capitalist mode of production – those who are in the same class – share common interests and should provide mutual assistance to each other

[9] "God has ordained the two governments: the spiritual, which by the Holy Spirit under Christ makes Christians and pious people; and the secular, which restrains the unchristian and wicked so that they are obliged to keep the peace outwardly... The laws of worldly government extend no farther than to life and property and what is external upon earth. For over the soul God can and will let no one rule but himself. Therefore, where temporal power presumes to prescribe laws for the soul, it encroaches upon God's government and only misleads and destroys souls. We desire to make this so clear that every one shall grasp it, and that the princes and bishops may see what fools they are when they seek to coerce the people with their laws and commandments into believing one thing or another." Luther (1523) *Von weltlicher Obrigkeit/On secular authority*.

[10] In the Jewish tradition, there is a phrase that means "all Israelites are responsible for each other". (*Kol yisrael arevim zeh lazeh*.) The origin refers to communal responsibility for an individual's sins. It is currently used in the sense of solidarity. *Arev* means "guarantee", and Jews speak of mutual guarantee *arvut hadadit* in the sense of support and backing. We are grateful to Dr Carmel Shalev for providing us with this information.

(see also Silver 1994: 550). Solidarity was seen initially as applicable exclusively to the working class, however, – as demonstrated by the internationalisation of workers' movements throughout the 19th Century – national borders were to be disregarded. In this sense, Marxist and socialist concepts of solidarity were (and are) significantly different from most contemporary calls for solidarity, where rights of people to goods and services are closely linked to national citizenship. A continuation of the Marxist and socialist traditions of solidarity among all members of a 'class' with no regard for national borders can be found, for example, in movements opposing global capitalism.[11] In these movements, however, the understanding of 'class' as the community of a group of people who occupy the same place in the production cycle has been replaced by the less clearly delineated group of those who are less privileged in their access to resources than the rich and ruling groups in their countries.

Trade union movements

1.16 The activities of labour movements played an important role in fostering awareness among workers of common goals, values and interest. This in turn made solidarity, here understood as a fellowship of people joined by a similar situation or fate, an important political notion which was both descriptive – in the sense just illustrated – and prescriptive, as it actively aimed to draw in and unite all those who were not active members of the movement. The need to provide mutual assistance to one's fellow workers also underpinned the beginning of the formation of trade unions in Europe in the second half of the 19th century.[12] In addition, trade unions were destined to help overcome the fragmentation of the working class.

[11] See, for example, *Notes from Nowhere* 2003; Reitan 2007. See also Brunkhorst's (2007: 109) notion of the turn from the "state-embedded public to public-embedded states". For the role in which social and other media give rise to new ways of relatedness, see Chapter 7 on the pandemics case study.

[12] For the history of trade union movements in the US and North America, see e.g. Galenson 1996.

Chapter 2

Recent developments and approaches

Chapter 2 – Recent developments and approaches

2.1 Bioethics is a field that has only recently developed. It is by its very nature interdisciplinary, with the involvement of many academic disciplines ranging from medicine to metaphysics, and philosophy to political science. Since there are no fixed borders between bioethics as a discipline and related areas, any inquiry into the uses of solidarity in bioethical writing should take account of the main uses of the term in these related areas. Because of the scope of this report, the following section cannot do justice to each of the complex, sometimes longstanding debates in other disciplines, such as for example, the discussions between modern liberal and communitarian political philosophers. Instead, here we offer some brief examples of the ways in which solidarity has been most prominently used in newer traditions that came after earlier Christian and socialist traditions. In order to prepare the next steps in the inquiry, we have where possible tried to select examples and authors that can be easily linked to debates in bioethics.

2.2 In the 20th century, the concept of solidarity has attracted interest mainly from communitarian thinkers. However, it has also played a role within other approaches, such as rational choice or feminist theory. Moreover, it remains an important concept in modern Marxist and Leninist discussions.

2.1 Solidarity and communitarianism

2.3 While in general, communitarianism – understood as an approach that propagates the need of societies to take the collective as a primary point of reference[13] – arguably dates back to the earliest days of political philosophy, the Stanford Encyclopedia of Philosophy (2009) refers to 'modern-day communitarianism' as having emerged as a reaction to John Rawls' Theory of Justice (1971). Among the most prominent proponents of this philosophical variant of communitarianism are Alasdair MacIntyre, Michael Sandel, Charles Taylor and Michael Walzer. The American-Israeli scholar, Amitai Etzioni – especially with his earlier works on the Spirit of Community: The Reinvention of American Society (1993) and New Communitarian Thinking (1996) – is seen as one of the founding fathers of political communitarianism, calling for a reassessment of the balance between rights and responsibilities in (mostly North American) societies.

2.4 Regardless of the differences between the different streams of communitarianist thought, and irrespective of whether they are of the philosophical or the political variant, bioethicist Alfred Tauber (2002: 24-25) regards contemporary expressions of communitarianist thinking as based on three theses:

i. Firstly, that communities cannot be reduced to individuals and their rights;

ii. Secondly, that community values are not simply the extrapolated values of the autonomous individual, but they must include the values of reciprocity, trust, solidarity and tradition; and

iii. Thirdly, that

[13] In contrast to utilitarianism, however, communitarianism assumes that the means to achieve desirable goals should also comply with shared moral and/or ethical norms. Thus, communitarianism is typically not consequentialist. Tauber (2002: 25), for example, describes the difference between communitarianism and utilitarianism as one where the principles of the former are broader than the principles of the latter: "In a communitarian ethic, the communal structure determines not only how choices are made, but more particularly what those choices might be as driven by concern for the community at large. These may be utilitarian, but they may also be driven by other goals or ideals. Whatever the communal ethic, the position of the individual is balanced within and against social needs." Roberts and Reich (2002) define the core unit of analysis in utilitarianism being the effect of an action, while communitarianism focuses on character and virtue.

> "the individual does not, and cannot, stand in a direct unmediated relationship with the state and society. There are, to be sure, degrees of choice and independence, but the notion of strict social, political, or ethical autonomy is regarded by communitarians as not only a conceit, but also as a distorting of the social reality."

"Most importantly", Tauber concludes, "the moral relation of the individual and the state demands a reciprocity of responsibility that places those values sustaining the community as paramount." (Tauber 2002: 25), and solidarity is regarded as such a value.

2.5 Of the many writers that express communitarian views, Alasdair MacIntyre's work is of particular importance with respect to his call for moral rationalities and argumentation that avoid the claims of absolute certainty or ultimate finality and relativist positions. In his book *After Virtue* (1981) he argues that the Enlightenment project failed in the task of providing us with moral structures. He believes that one of the reasons for this – and this is of particular relevance in the context of solidarity – is that Enlightenment rendered the individual the central bearer of moral agency, so that morality and ethics became individual enterprises. This change had the effect of stripping central virtues of their deeper meaning:

> "In a society where there is no longer a shared conception of the community's good as specified by the good of man, there can no longer either be any very substantial concept of what it is to contribute more or less to the achievement of that good. Hence notions of desert and honour become detached from the context in which they were originally at home. Honour becomes nothing more than a badge of aristocratic status, and status itself, tied as it is now so securely to property, has very little to do with desert. Distributive justice cannot any longer be defined in terms of desert either, and so the alternatives become those of defining justice in terms of some sort of equality [...] or in terms of legal entitlements. And justice is not the only virtue that has to be redefined (MacIntyre 1981: 215-216)."

2.6 MacIntyre's critique of a "society where there is no longer a shared conception of the community's good" is embedded in a larger critique of liberal capitalism, where protest and resistance have become the characteristics of 'public debate'. For MacIntyre, our ethics should be guided by virtues, which for him are not abstract norms deferred from larger abstract principles, but are grounded in shared beliefs and practice. In developing this notion, MacIntyre draws upon Aristotle's ethics (and in particular his concept of teleology; rules are based on virtues which are derived from the (shared/common) end or goal, the *telos*), as well as the work of Thomas Aquinas.

2.7 MacIntyre' work has inspired a number of authors writing more specifically on bioethical topics. One of the most prominent exponents of communitarianism in bioethics is Daniel Callahan (1999, 2003). Similar to some of MacIntyre's arguments, Callahan sees the need for a communitarian perspective as emerging from the prevailing perspective of liberal individualism in bioethics.[14] The distinctive characteristic of communitarianism, he argues, is that it does not only consider the effect that an action, measure, or policy has on the flourishing of individual entities, but that it is also concerned with wider implications. These include implications on human nature, the relationship between the public and the private, the welfare of the whole, human rights, participation, and the relationship between the individual and the common good. He illustrates this with an analogy:

> "The important question for ecologists when new species are introduced into an existing environment is not just how well they will flourish individually, but what they will do to the network of other species. Will they live in harmony with them, perhaps improving the whole ensemble, or will they prove destructive? Or will they perhaps do a little of both? The function of communitarianism is to force us to ask the ecology question, now brought into the realm of ethics (Callahan 2003: 503)."

[14] See also Bellah et al. (1985), who call individualism America's "first language" (Bellah et al. 1985: 20), or, as Stout (1988: 193) circumscribes it, as "the moral vocabulary Americans share".

2.8 A communitarian perspective is further seen to entail that one does not "avoid substantive analysis and judgement", but instead tackles "the hardest and deepest questions about the right uses of medical knowledge and technology" (Callahan 2003: 505). Communitarianism, according to Callahan, does not offer a formula or a set of criteria to carry out such analyses; instead, it is best understood as a way of framing issues.

2.9 Callahan does not suggest that liberal individualism should be simply replaced with communitarianism; instead, communitarianism should be seen "to be a strong competitor – permitted, in fact, to make the opening bid in framing the issues" (Callahan 2003: 502). Liberal individualism and communitarianism are not mutually exclusive, he argues, as 'many well-accepted principles reflecting a commitment to liberal individualism can be converted into communitarian principles, and […] they will be richer for it' (Callahan (2003: 505). Callahan understands solidarity to be the practice of members of a group or society contributing towards establishing and then protecting a common good. He explicitly calls for the introduction of solidarity into the debate on rationing resources in medicine and public health, where the continuing existence of an affordable health care system providing basic services is taken to be the common good (Callahan 1999).

2.10 One of the rare works that explicitly addresses the relationship between the "communitarian turn" (Chadwick 1999; see also Sutrop & Simm 2011) in ethics and increased use of solidarity is Knoppers' and Chadwick's (2005) piece on emerging trends in ethics in the context of human genetic research. Communitarianism, these authors argue, has challenged the hierarchy between dominant values in ethics (particularly with respect to autonomy), as well as extending the range of values that serve as points of reference in ethical reasoning. Reciprocity, mutuality, citizenry, universality, and solidarity, are such points of reference. With regards to solidarity specifically, Knoppers and Chadwick distinguish *communal solidarity*, understood as existing shared practices, from *constitutive solidarity*, where the bond of solidarity is a common interest shared by a group of people (for a slightly different distinction between two kinds of solidarity using the same terms see Husted 1999).[15]

2.11 In sum, the concept of solidarity envisaged by communitarians centres around the preservation of a particular shared understanding of society and its goals as well as a shared idea of the good life – in short, it is based on a common good. Such a substantive, 'thick' understanding of the good is one of the main tenets of communitarianism. However, it is this idea that invites most of the criticism from liberal critics.[16] Firstly, they doubt that such a common good exists in modern pluralistic societies. And secondly, they perceive the collective striving towards such a good and the expectation that members of society need to show solidarity with each other and with collective institutions, as autocratic and absolutistic. In fact, as Stout (1988) summarises, liberal writers sometimes criticise communitarian designs of society not because they see liberal designs as fairer or more just (Meilaender 1983), but because the communitarian alternative bears even greater dangers: "Communitarians are to be distrusted because they call us into a kind of solidarity with others in public life that would be disastrously totalitarian, threatening our private bonds and spiritual freedom" (Stout 1988: 233). This structure of the critical argument against a common good is one of the reasons why modern liberal and liberal egalitarian thinkers invoke solidarity rather rarely.

2.2 Solidarity and rational choice

2.12 Rational choice theory is another strand of modern thought employing solidarity, albeit in a different way and exhibiting a very different understanding of it than the aforementioned

[15] While we consider Knoppers' and Chadwicks' discussion of the five new reference points in ethics as extremely informative, their distinction between communal and constitutive solidarity is less fruitful: existing shared practices can be linked to a common interest, and common interests can be embedded in shared practice.

[16] Of course, criticism of communitarian arguments does not come from liberal thought alone: Loewy and Springer (2007: 262) call "parochial communitarianism" the way in which "[s]ome religions may include only their own members and some secular groups of persons may limit such obligations to other members of their own race or community".

communitarianism. Sociologist Michael Hechter (1987) is the most prominent scholar in the rational choice tradition who wrote about solidarity. Like Søren Holm (Holm 1995; Holm nd) and others, he sees groupness as the core property of solidarity, yet he endorses a very particular understanding of the term, stemming from his long-standing interest in how to explain individual behaviour. Groupness, in Hechter's understanding, is "the group's capacity to affect the member's behaviour [… . T]he more solidary a group, the greater the influence it casts upon its members" (Hechter 1987: 8). Hechter's approach to solidarity is based upon the assumption that people deliberately form or join groups in order to consume excludable jointly produced goods (Hechter 1987: 10). Insofar as group members comply with group rules out of a sense of obligation (not fear of coercion), they act out of solidarity. Hechter proposes a formula for the assessment of the level of solidarity within a group:

> "a group's solidarity is a function of two independent factors: first, the extensiveness of its corporate obligations, and, second, the degree to which individual members actually comply with these obligations. Together, these provide the defining elements of solidarity. *The greater the average proportion of each member's private resources contributed to collective ends, the greater the solidarity of the group*" (Hechter 1987: 18; original emphasis).

2.13 Hechter does not derive any conclusions with regards to substantive political or ethical arguments from his understanding of solidarity; instead, he develops a model with the explicit aim of allowing rational-choice oriented social scientists to operationalise solidarity, a notion which some social theorists and scientists allegedly relegate "to darker corners of their intellectual realms, or [ignore] altogether" (Hechter 1987: 168). Although Hechter considers the empirical evidence for the prevalence of group solidarity as "far from conclusive", in his book he attempts to show "how a small set of behavioral assumptions can elucidate macrosociological processes by taking both social structures and individual actors into account" (Hechter 1987: 168).

2.3 Contractual solidarity

2.14 Another prominent interpretation of a core meaning of solidarity is to understand it within a contractual framework. Houtepen and Ter Meulen (2000a: 329) unpack the meaning of the term solidarity in the context of welfare state design, and argue that 'the form of solidarity embodied in the provision of care and access to care in European societies' has changed radically in the last decades:

> "The spontaneous voluntary solidarity in the reciprocal arrangements of support and care within well-defined groups and communities has given way to comprehensive systems of organised and enforced solidarity that have evolved within modern welfare states. With the collectively financed risk-sharing arrangements of care, covering all citizens, each with equal right to care, *solidarity has assumed the form of contractual solidarity in welfare* [our emphasis]."

2.15 Bayertz (1999: 22) states that a contractual understanding of solidarity underpins the concept of the welfare state: "Characteristic of the welfare state is not that it consists of *moral* ideals or duties to support the needy, but that this support is legally institutionalized by the state" [original emphasis]. It should be noted, however, that this notion of solidarity is challenged by some authors who differentiate between solidarity and other forms of assistance according to whether or not the provision of assistance is based on a contractual relationship (e.g. Wildt 1999: 217; Baurmann 1999: 243). In other words, if someone gives something to someone else – either directly in the form of payment, or indirectly via contributing to transfer payments via paying one's tax – because the receiver has a right to the reception of the good or service, the giving is seen as not being based on solidarity.

2.16 One problem with such a narrow interpretation of contractual solidarity is that it leads to highly counter-intuitive results. Giving may occur within a contractual relationship but still be based on close interpersonal bonds and the perception of need in the receiver. Examples of this would be

parents who give various things and goods – food, attention, clothes – to their children. In many societies, they are obliged to do so by law, but few would argue that there are therefore no other, emotional or social, bonds involved. Another example would be opt out (presumed consent) systems in organ donation, such as they exist e.g. in Austria. Although in such a system, physicians have the right to take someone's organs *post mortem* unless the deceased person explicitly stated the contrary, this right does not preclude any feelings of solidarity by the donor towards people needing organs being the root of that person's motivation to be an organ donor. Simply put: just because the doctor has the right to take the organs, does not mean the deceased could not have been motivated by solidarity.

2.17 Some authors implicitly support the understanding that solidarity is never based on contractual duties, although they use slightly different terms (e.g. Jodi Dean [1996: 12] when, in her book *Solidarity of Strangers*, she argues that "[w]e don't *demand*, we *appeal* to solidarity" [original emphases]. Ter Meulen et al (2010: 7) also support this view when they say that "solidarity connotes voluntary action"; however Ter Meulen and colleagues also introduce the helpful distinction between solidarity as a community value as opposed to solidarity as a system value (Ter Meulen et al. 2010: 11). The latter – solidarity as a system value – can contain articulations of solidarity in formal/legal arrangements.

2.4 Solidarity and gifts

2.18 Although we believe altruism can be distinguished from most core interpretations of solidarity (see Chapter 4), altruism and solidarity are sometimes used simultaneously. The best known work on altruism in modern society is Richard Titmuss' work on the gift relationship. Titmuss (1970) famously compared systems for blood donation, where blood donors were paid (such as in the US), with systems based on altruistic donation (such as the UK). Titmuss concluded that altruistic donation systems were not only morally more desirable, as they rejected "the possessive egoism of the market place" (Titmuss 1970: 13), but also safer and more efficient. Titmuss understood gifts as manifestations of relationships between people.[17] Although solidarity as an explicit value is not prominent in Titmuss' work, Waldby and Mitchell (2006) provide a very fruitful discussion of the relevance of Titmuss' gift relationship in terms of solidarity. For example, they analyse that "[g]iving blood to the troops was a way to express solidarity and improve morale in the anxious conditions of world war" (Waldby & Mitchell 2006: 3). This does not only apply to the world wars of the 20th century but also to the terrorist attacks of the new century (see also Starr [1998: 154], who saw blood donation as a symbol of a new social contract).

2.5 Reflective solidarity

2.19 Jodi Dean (1996) speaks of "reflective solidarity",[18] which aims at combining solidarity with a positive approach to differences. This approach centres on the importance of openness and inter-individual relationships. Reflective solidarity, Dean (1996: 29) argues, "refers to *a mutual expectation of a responsible orientation to relationship*" [original emphasis], by which responsibility signifies that we are accountable for excluding others, and "orientation to relationship' recognises that we can acknowledge our mutual expectations without hypostatising them into a restrictive set of norms". Coming from a feminist political theory background, Dean's main normative argument is formulated in procedural terms: reflective solidarity should

[17] Titmuss' concept of the gift differed greatly from the pioneering work of Marcel Mauss (1990, first published in 1924) who had described practices of gift exchange in Polynesia. Mauss drew attention to the reciprocal character of gift-giving, where the refusal to accept a gift, or the unwillingness to reciprocate, would mean a declaration of war. Thus, the gift relationships described by Mauss are not based on common understandings of altruism as a general attitude of helping others without thinking of my own benefit or expecting anything in return, but de facto contractual relationships (where sanctions follow when one does not meet one's end of the tacit agreement; see also Derrida 1992).

[18] A similar term –"reflexive solidarity" – is employed by Houtepen and Ter Meulen (2000b: 367) when they suggest that linking the work of political theorist Herman van Gunsteren (1998) with Anthony Giddens' (1994) work "offers important clues to develop a joint approach to democratic citizenship and reflexive solidarity" (see also Beck et al. 1993).

> "require us to rethink the boundaries of community, the demarcation between 'us' and 'them'. [… It] conceives the ties connecting us as communicative and open. This openness creates a space for accountability, enabling us to grasp the ways this notion of solidarity no longer blocks us from difference, but instead provides a bridge between identity and universality (Dean 1996: 30)."

2.20 Thus, according to Dean, our main ethical duty with respect to solidarity is that we reflect on practices and institutions of exclusion both with regards to their criteria as well as their scope. In other words, Dean calls for a sustained effort of making explicit the underlying substantive values and norms that make us feel and enact support for some people rather than others. It is noteworthy that Dean's notion of reflective solidarity does not require that one is willing to modify one's self- understanding or identity (even if it is particularistic). In a nutshell, Dean's mobilisation of solidarity amounts to a call for tolerance and communication. Dean is less explicit with regards to what enactments of solidarity – as opposed to enactments of exclusion – can and should look like. It is apparent, however, that establishing reflective solidarity in society and politics would lead to the inclusion of greater groups of people (e.g. minorities or women) into "notions of civil society" (Dean 1996: 75; see also Habermas 1998; Pensky 2007) simply because their exclusion cannot be politically argued. In other words, Dean's reflective solidarity could lead to greater inclusion because it renders the criteria and scopes of exclusion visible, which in turn opens them up for negotiation.

2.6 Agonistic solidarity

2.21 In general, agonism describes a number of political and social theorists who hold that it cannot, or even that it should not, be the role of political systems to overcome conflict. Thus, the main question that agonists are concerned with is how difference and conflict can and should be dealt with, instead of how it could or should be overcome. The work of political theorists Chantal Mouffe and Ernesto Laclau has been particularly influential in this context (e.g. Laclau & Mouffe 1995; Mouffe 2000; see also Norval 2007).

2.22 Gunson (2009: 249) provides one of the rare explicit references to agonism in connection with solidarity when he notes that solidarity, by calling for, or describing, inclusive and cohesive forces regarding a particular group, is necessarily exclusive of those outside of this group.[19] In other words, solidarity includes mechanisms that prevent it from being extended to other groups (see, however, Christian, and in particular, also Catholic understandings of solidarity, where it is seen as applicable to all human beings, see Chapter 1). So far, however, as an explicit term, 'agonistic solidarity' has not been influential in ethical, social, and political theory.

[19] See also Heyd (2007: 11), Jaeggi (2010: 290) and Putnam (2000: 23: "Bonding social capital, by creating strong in-group loyalty, may also create strong out-group antagonism"). The work of other authors could be seen as implicitly contributing to an (emerging) notion of agonistic solidarity: Jodi Dean (1996: 19), for example, emphasises the inherent property of solidarity to always exclude those which it does not include (see also Lenhart 1975; Rorty 1989).

Chapter 3

Solidarity in recent bioethical writings

Chapter 3 – Solidarity in recent bioethical writings

3.1 References to solidarity in bioethics have increased over the last few decades. In the following chapter, we present the outcomes of an extensive literature analysis. Based on a systematic search, as explained in the methods of working (see Introduction), the main part of the analysis focused on the most recent and most cited works on solidarity in bioethical writings). Due to how the discussion has developed, most of these works are from the last decade of the 20th century and the first decade of the new millennium. The term 'bioethical writings' in this context also includes work in public health insofar as it either: (1) had 'bioethics' in the title, keywords, or abstract; or (2) it is prominently discussed in bioethical literature in the stricter sense of the word, or (3) both.

3.1. Explicit and implicit references to solidarity

3.2 Despite the fact that the frequency of mentions of the term solidarity has increased in public discourse, explicit references to the term solidarity are relatively rare in recent bioethical writings, compared to other terms such as autonomy, justice, privacy, equity, futility, identity etc. Few articles make explicit reference to solidarity in their title, abstract, or keywords; less than a dozen books are devoted to this topic (even fewer when one does not include those in political philosophy/ethics) and neither textbooks nor compendia – such as for example the *Oxford Handbook of Bioethics* (Steinbock 2007), Beauchamp and Childress' *Principles of Biomedical Ethics* (2001), Ashcroft et al.'s (2007) *Principles of Health Care Ethics*, or the online publication *Stanford Encyclopedia of Philosophy*, all of which represent important resources for bioethicists – contain dedicated chapters discussing solidarity. Moreover, it does not play a prominent role in books devoted to an analysis of bioethics as a discipline. For example, Renée Fox's and Judith Swazey's book *Observing Bioethics* (2008), which provides a reflection on the history of (institutionalised) bioethics from the perspective of two authors who were involved in the field and important observers from the beginning, does not address solidarity explicitly (although the book is quite explicit in its critique of the prominent role of autonomy in North American, and partly also European, bioethics).

3.3 A first interesting finding of the analysis was that solidarity as a concept, an idea, or a value, was much more prominent in bioethical writings than the frequency of explicit uses of the term would have suggested. In other words, there was a discrepancy between the number and scope of discussions in which the term solidarity was employed explicitly (those are discussed below), and those discussions where situations, norms, and dilemmas were associated with solidarity by some authors but not others. For example, whenever discussions focussed on the balance between individual rights and the common good, mutual assistance and altruism, or arrangements to mitigate and compensate for risks, these discussions arguably concerned solidarity. We expect that with more explicit focus on solidarity and more analysis such as the work we present in the report, these discussions will take the term on board to reframe some of the issues at stake. We therefore predict that with increasing clarity of what solidarity means and what it can do in bioethical discourse, its rise to prominence will continue further.

3.2 Definitions of solidarity in bioethical writing

3.4 The following section presents an overview of the specific definitions that have been developed by bioethicists or other academics working on bioethical questions over the last two decades. Some of these are derived from or follow on from some of the definitions discussed in the last chapter.

3.5 Reflections on recent uses of solidarity frequently emphasise the tendency of the concept to cut across several political, philosophical, and social dimensions and categories. Houtepen and Ter Meulen (2000a: 334) provide a succinct overview of the various ways in which the term

'solidarity' has been employed, ranging from cases where solidarity is used in a context where symmetrical[20] relationships between people are presumed or promoted (i.e. where people are equal to each other: e.g. brotherhood, fellowship), to uses which assume asymmetrical relationships (where people are in an unequal relationship to each other, e.g. charity). Sometimes, Houtepen and Ter Meulen argue,

> "solidarity is ascribed to individuals (sympathy for the weak), at other times to communities (social cohesion). Solidarity may be described as primarily a relationship between individual persons (altruism, fellowship) or rather as an institutional relationship (citizen's duties). The scope attributed to solidarity may tend either to include 'outsiders' (universal brotherhood) or to exclude them (ethnic rallying together). Solidarity may be distinguished from friendship (too strong), interest coalitions (too weak), loyalty (too particularistic), compassion or humanitarian aid (too private, noncommittal and a-symmetrical) […]."

3.6 Houtepen and Ter Meulen themselves promote a notion of 'reflexive solidarity' (see above), where solidarity "is not primarily about the motivation of individuals or the outcome of distributive processes, but about the sort of intersubjective relations required to keep the fabric of modern society intact" (Houtepen & Ter Meulen 2000b: 374).

3.7 Kurt Bayertz (1996: 308) subsumes under the label of solidarity "acts carried out in order to support others, or at the very least to describe a disposition to help and assist". Besides social justice and an economic policy based on maximum employment, solidarity is one of the foundations of the welfare state and publicly funded health care systems, but definitions vary as to how it should be understood.

3.8 Kees Schuyt (1995: 298) defines solidarity as a commitment to making sure that "nobody should drop below the level necessary for a decent existence in a free society".[21] This definition is interesting, as it could be argued that the objective that no one should drop beyond a certain level in society can be – and frequently is – justified by recourse to a variety of other values, such as human capabilities, well-being, or flourishing; human rights; or principles such as Rawls' difference principle.

3.9 With regards to the institutional arrangements that could be justified according to Schuyt's notion of solidarity, Darryl Gunson (2009: 251) notes that "solidarity is merely one way of organising our social institutions. When they cease to deliver the goods, so to speak, then alternative arrangements need to be considered".

3.10 Berlin-based philosopher Rahel Jaeggi (2010: 287) understands "solidarity as a certain kind of cooperation that can be related to Hegel's concept of 'ethical life' (*Sittlichkeit*)", a form of "standing in for each other" which is "neither given nor invented" (Jaeggi 2010: 288). Welfare theorists Wim van Oorschot and Aatke Kompter (1998) see solidarity "primarily as a state of relations between individuals and groups enabling collective interests to be served". Bioethicist Matti Häyry (2005: 204) sees "non-calculating co-operation" as "the essence of solidarity". This definition contains the notion of mutual assistance which features prominently in the political genesis of the concept. It also stresses the willingness for this assistance being[22] non-instrumental in the sense that it does not materialise in expectation of future benefits or reciprocation (see also Schmidt 2009: 139, and Chapter 4 on reciprocity and social capital). Looking back at the question of whether the granting of assistance (in whatever form) on the basis of contractual relationship should not be seen as based on solidarity (see Chapter 2), Häyry not only affirms this, but takes an additional step. In his view, in order to meet the

[20] Jaeggi (2010) is one of the very few scholars referring to symmetry in the context of solidaristic relationships; yet she also uses terms "hierarchical" and "non-hierarchical".

[21] The definition appears in a list of definitions of key terms. It reads literally: "Solidarity: nobody should drop below the level necessary for a decent existence in a free society".

[22] Or having to be – this remains unclear.

requirement for solidarity, not only must assistance not be based on contractual obligations, but neither must the underlying motivation be the expectation that one gets something in return. People's motivations must in effect be 'purely' altruistic. This firstly raises the question of how this definition of solidarity can be distinguished from altruism; in fact, both terms appear to collapse into each other in this approach. Secondly, like many applications of altruism, this invites the practical problem of applications being based on motivations of people, which are notoriously difficult to assess and operationalise (see e.g. Siegal and Siegal 2009). We will return to this issue when debating our working definition in Chapter 4.

3.11 The recent report on biofuels by the Nuffield Council on Bioethics (NCoB 2011) proposes a definition of solidarity which takes it to govern the relationships and obligations between populations. Discussing solidarity in the context of global climate change, the report appeals to people sharing a common situation or fate. It further stresses the need to protect vulnerable groups, thus including an element of asymmetry:

> "Solidarity focuses on the importance of protecting individuals as members of groups or populations. It is the idea that we are all 'fellow travellers' and that we have duties to support and help each other and, in particular, those who cannot readily support themselves. In the context of biofuels, the value of solidarity directs ethical attention to the most vulnerable people within societies, reminding us that we have a 'shared humanity', a 'shared life' and that those who are most vulnerable should be given special attention." (NCoB 2011: xxiv)

3.3 Solidarity in bioethics: contexts and issues

3.12 The literature analysis provided a clear finding regarding the content in bioethics that is discussed by recourse to the term solidarity. Where they exist, explicit references to solidarity appeared mainly in four different contexts within the bioethical literature:[23]

v. Firstly, in the context of **public health**, where solidarity was regularly discussed as a value capable of justifying the comparably stronger involvement of state authorities in public health;

vi. Secondly, in the context of **justice and equity of healthcare systems**;

vii. Thirdly, when it was invoked normatively in connection with providing assistance to poor countries and societies in the context of **global health**; and

viii. Finally, when it was referred to as a **European, as opposed to an American, value**. This latter point cuts across all other domains: it becomes pertinent when European healthcare systems are contrasted with US healthcare, or when the role of autonomy in bioethics is discussed.

3.13 Another conclusion can be drawn when considering these four contexts; and this conclusion will be explored in more detail in the sections below. All four of these contexts represent relatively young areas of exploration in bioethics. As recently as 2007, for example, Dan Brock and Dan Wikler called for a broadening of the bioethical agenda to include a public health and a global health perspective, both of which they considered to be sorely neglected within the bioethical discourse (Brock/Wikler 2007). Questions of justice in the allocation of scarce healthcare resources have been discussed for several decades. Until the end of the 1980s, however, this was an almost exclusively Anglo-American debate, dwarfed by other bioethical topics that centred around clinical issues and those brought on by developments in biomedicine, such as transplantation, reproductive medicine or genetics, and questions around patient's rights, including the right to die or the right to have an abortion. With increasing financial pressure on healthcare systems, the discussion has taken more prominence in the UK and the US over the

[23] The work of the Nuffield Council on Bioethics presents an exception to this rule. In addition to its report *Public health: ethical issues*, discussed further below, solidarity is mentioned as part of the ethical frameworks in the report on dementia (NCoB 2009) and the aforementioned report on biofuels.

last two decades. Simultaneously, it has entered the continental European literature, and questions of justice and equity in healthcare systems now rank amongst the liveliest debates in bioethics anywhere in the world. Regarding Europe, the whole discipline took longer to develop there: up until the late 1970s Anglo-American institutions and authors dominated the field, and it took time for Europe (and other continents as well) to catch up and establish the field. Therefore, questions such as whether there are specific European values in bioethics have only been taken up during the last two decades; before that, there was little reason to reflect upon a field that was in its early infancy. It is therefore no coincidence that solidarity has risen to more prominence over the last decades, since this is exactly the time during which the four areas developed from small side-issues in bioethics into full-blown bioethical debates engaging academics, policy makers and the public in equal measure.

3.14 As we will lay out in more detail below, all four areas invite invocations of solidarity because they focus on questions beyond the individual patient, addressing societal issues and the different relationships these play out in, including arguments about the actors in these relationships as well as responsibilities, obligations and claims. For example, it is on account of the focus on collective measures within public health that the connections between humans and social actors, rather than these humans and social actors themselves, are in the centre of attention of many scholars in the field.

3.4 Context 1: Solidarity and public health ethics

3.15 The US Institute of Medicine's famous definition of public health describes the field as that "what we, as a society, do collectively to assure the conditions in which people can be healthy" (Institute of Medicine 1988: 1).[24] This focus on collective action and public measures[25] helps to understand why the notion of solidarity is invoked more explicitly, and much more frequently in the field of public health than in other areas of bioethics. In fact, some refer to this focus as a reason to contrast bioethics and public health ethics: Callahan and Jennings (2002: 170) speak of a "tension produced by the predominant orientation in favour of civil liberties and individual autonomy that one finds in bioethics, as opposed to the utilitarian, paternalistic, and communitarian orientations that have marked the field of public health throughout its history" (see also O'Neill 2002b; O'Neill 2003;[26] Callahan 2003; Widdows 2011: 85, and Jennings' [2001] notion of "possessive individualism"). Tauber (2002: 23) diagnoses an "interesting tension" inherent in the history and remit of public health: "within a political culture organized around legal autonomy, public health operates by a communitarian ethic", which in turn also distinguishes public health from bioethics. It is not surprising that authors whose work is more strongly informed by communitarian thinking have devoted earlier and more attention to public health ethics than others. In the following, when presenting the perception of solidarity that a number of authors take in the public health context, we also describe in brief their understanding of the field of public health and public health ethics.

The NCoB report on Dementia and the partnership model

3.16 Dementia is an increasing challenge for public health. In its report *Dementia: ethical issues*, the NCoB (2009) highlights and develops the concept of solidarity (later mirrored in NCoB's report on biofuels). Solidarity is defined as "the idea that we are all 'fellow-travellers' and that we have duties to support and help each other and in particular those who cannot readily support themselves" (NCoB 2009: 29).

[24] For a much wider understanding of what definitions of public health include, see e.g. Coggon (2010).
[25] On this see also Childress et al. (2002).
[26] O'Neill (2003: 84-85) proposes the concept of principled autonomy, which she understands as a "matter of acting on certain sorts of principles, and especially on principles of obligation", whereby it is important that those principles "could be adopted by all others". Thus O'Neill's approach weaves the communal dimension into the autonomy concept. It has had a profound impact on the field of bioethics (e.g. Stirrat and Gill 2005).

3.17 A "requirement to act in accordance with solidarity", which is described as "the need to recognise the citizenship of people with dementia, and to acknowledge our mutual interdependence and responsibility to support people with dementia, both within families and society as a whole", is put forward as a key component of an ethical framework for the way we and our society addresses and deals with dementia (NCoB 2009: xviii). In terms of substantive recommendations, the report derives from the value of solidarity the "moral imperative to tackle the stigma" associated with the condition, and the commitment to supporting research into dementia. Moreover, the focus on solidarity is seen as emphasising "the need to both act to protect the person with dementia and to support their carer where the person with dementia continues to benefit from their care" (specific recommendations as to what this entails are outlined in the report). The relational approach to autonomy that the report advocates – namely that people's interests and decisions are seen as connected with the social relations they have (NCoB 2009: 117) – leads to a wide understanding of professional support in the context of dementia: support thus not only entails support for the person with dementia, but also for her family and others who help and care for her (NCoB: 118). The report further emphasises that the support that people with dementia deserve to receive is grounded in their being citizens, and not in their being victims of a disease. It thereby highlights the ethical requirement to treat those who receive support as equals (NCoB 2009: 30; see also our working definition of solidarity in Chapter 5). The report's approach towards caring for people with dementia can therefore best be described as one of partnership (NCoB 2009: 119), which entails the imperative for social inclusion of those suffering from the condition, as well as their family and carers.

Public health ethics and solidarity: personalism

3.18 Italian public health experts Carlo Petrini and Sabina Gainotti (2008: 624) mention three main reasons why neither common ways of reasoning nor substantive values or arguments in bioethics can be neatly translated into public health ethics. These relate to, first of all, "the [lack of] adaptability to public health of the classical principles of bioethics"; second, to the aforementioned "duty to respect and safeguard the individual while acting within the community perspective that is typical of public health", and third, to "the application-oriented nature of public health and the general lack of attention towards the ethical implications of collective interventions [in public health] (compared with research)". Petrini and Gainotti develop what they call "a personalist approach to public-health ethics" (2008: 626-627), whereby "[p]ersonalism strongly emphasizes the need to protect the weakest and the sickest persons in society. In a personalistic view, the being and dignity of the person are fundamental and inalienable values". Because personalism does not simply exclude negative behaviours but requires positive attitudes, the authors argue, it must not be equated with individualism, which treats individual autonomy as constitutive of the person. Personalism, in contrast, regards "our common shared human nature" as at least equally constitutive of personhood (Petrini & Gainotti 2008: 626). As personalist principles pertinent to public health, they name – in a demonstrative manner – "respect of the individual's autonomy, the safeguard of confidentiality within a collective and potentially de-personifying framework, the effort to guarantee equity and equal opportunities for everyone in the allocation of health-care resources" (Petrini & Gainotti 2008: 626; see also Churchill 2002). The authors refrain from specifying the concept of personalism beyond these very general terms; in addition, they note that personalism overlaps with other "theories" (Petrini & Gainotti 2008: 626; see also Petrini 2010a, b), again without specifying in what respects in particular they overlap and differ. This begs the question of the analytic value of their personalist approach.[27]

[27] It should be noted that although Petrini and colleagues have introduced the personalist approach into public health ethics, personalism *per se* is not an invention of these authors. The *Stanford Encyclopedia of Philosophy* (2009) highlights the origin of personalism in (particularly Catholic, Thomistic) Christianity, which Petrini and colleagues do not explicitly refer to. It attributes the term personalism to F.D.E. Schleiermacher in his book *Über die Religion* (*On Religion*), 1799. In the English speaking world, Walt Whitman coined the term American personalism in his *Personalism*, published in the May 1868 issue of *The Galaxy*. The *Stanford Encyclopedia of Philosophy* states that personalism "arose as a reaction to impersonalist modes of thought which were perceived as dehumanizing." Yet the "emerging personalist philosophy […] rejected impersonalism not only in the form of idealistic or materialistic determinism and collectivism, but also in the form of the radical individualism that

3.19 The authors make explicit reference to solidarity (Petrini & Gainotti 2008: 627) by arguing that "personalism strongly values principles of sociality and solidarity. However, the individual's good is the basis for common good". This sentence reiterates the earlier statement that personalism sees human beings as *equally* constituted by individual autonomy and shared human nature.

3.20 Although Petrini and colleagues applied their concept of personalism to the concrete cases of triage (Petrini 2010b) and pre-emptive transplantation (Petrini 2009[28]), these cases fail to show how a personalist approach to public health ethics provides insights or normative conclusions that could not be obtained on the basis of other approaches, such as altruism (see also Petrini 2010a, and Petrini et al. 2010).

Public health ethics and solidarity: stewardship

3.21 The NCoB's report *Public health: ethical issues* joins the ranks of those who criticise the focus of ethical approaches in the realm of health as being too much focused on individual health and individual autonomy. The field of public health is seen as lending itself to the challenge of the dominant position of individual autonomy by its very nature; public health is understood as referring

> "to the efforts of society as a whole to improve the health of the population and to prevent illness. The emphasis of public health policy on prevention rather than treatment of the sick, on the population as a whole rather than the individual, and the importance of collective effort, poses a particular set of ethical problems. […]This means that the notion of individual health determining health is too simplistic." (NCoB 2007: v)

3.22 The report developed the "stewardship model" of the state in relation to public health, a model which

> "recognises that the state should not coerce or restrict their freedoms unnecessarily, but also that the state has a responsibility to provide the conditions under which people can lead healthy lives if they wish. The stewardship state, in addition to protecting its citizens from harm caused by others, sees itself as having a particular responsibility for protecting the health of vulnerable groups such as children, and in closing the gap between the most and least healthy in society." (NCoB 2007: v)

Moreover,

> "[t]he concept of 'stewardship' is intended to convey that liberal states have a duty to look after important needs of people individually and collectively. It emphasises the obligation of states to provide conditions that allow people to be healthy and, in particular, to take measures to reduce health inequalities. The stewardship-guided state recognises that a primary asset of a nation is its health: higher levels of health are associated with greater overall well-being and productivity." (NCoB 2007: xvi)

3.23 Thus, the stewardship model of the NCoB report *Public Health: ethical issues* resonates with approaches that conceive health as a public good; as such it is by definition the role of governments to provide (access to) the resource to all of its citizens. In the context of health, the

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was equally a product of modern rationalism and romanticism, and which, through, for instance, certain forms of liberalism and anarchism, was also characteristic of the nineteenth century." The so-called 'Leuven personalism', developed at the Catholic University of Leuven in Belgium since the 1930s understands religious and secular values as being complementary (De Wachter 1998). The smallest denominator of personalist thought includes "an insistence on the radical difference between persons and non-persons and on the irreducibility of the person to impersonal spiritual or material forces, an affirmation of the dignity of persons, a concern for the person's subjectivity and self-determination, and particular emphasis on the social (relational) nature of the person." With regards to the latter, as personalists stress the person's nature as a social being, it is the case that "*interpersonal relations* are never superfluous or optional to the person, but *are constitutive of his inherent make-up and vocation"* [our emphasis].

[28] For example, the author derives from his personalist approach to public health ethics the requirement to "promote a correct culture of donation" (Petrini 2009: 173).

role of the state is to ensure that citizens have access to the lifestyles, services, and resources that enable them to remain healthy or obtain treatment.

3.24 The NCoB makes explicit reference to the term solidarity six times in total, two of which pertain to global solidarity (see chapter 6). [29] However, the term solidarity does not play a central role within the framework that informs the report's recommendations, which are based on the stewardship model. In fact, the NCoB prefers the term "community" to describe the "shared commitment to collective ends", where the latter reaches beyond individual welfare. This commitment underlies the support of collective public health programmes.

Public health ethics and solidarity: the relational approach

3.25 Francoise Baylis and colleagues (2008: 196) argue that the "near pandemic" of SARS in 2003 has triggered renewed interest in public health, which provides new opportunities for foregrounding solidarity. Their relational approach contains four different dimensions:

a Relational Personhood: Following Charles Taylor's work on selfhood (Taylor 1989), this notion criticises conceptualisation of personhood as "independent, rational, self-interested deliberator[s]", who are "separate from one another, each with his or her own private interests that must be respected and accommodated as far as possible [… I]n these circumstances, the larger social contexts that patients and research participants inhabit tend to be treated as either irrelevant or as obstacles to their autonomy" (Baylis et al. 2008: 200). Such perspectives neglect, as the authors argue, that we all "develop within historical, social, and political contexts and only become persons through engagement and interaction with other persons" (Baylis et al. 2008: 201). Thus not only our self-understandings, but also our decision-making is relational. In sum, "[p]ublic health ethics needs to begin with a relational understanding of persons that is attentive to ways in which patterns of systematic discrimination or privilege operate in terms of the goals and activities of public health" (Baylis et al. 2008: 201; see also Powers & Faden 2006). The authors regard feminist work as

[29] The report makes explicit reference to the notion of solidarity:
(1) When it says that the case studies examined in the report "consider the role of autonomy, consent and solidarity" as a point of reference, besides "the variety of aims for such measures, such as informing individual choices and protecting the wider communities and their relative priorities", "issues raised by decisions about, and perceptions of, risk", and "the special situation of children and those who are poor or socially excluded" (NCoB 2007: x);
(2) When it argues that policies in the provision of healthcare that single out "obese people could also substantially undermine the concept of solidarity and the value of community" (NCoB 2007: xxvi, and 5.42 on p97);
(3) In the section on "the value of community" (NCoB 2007: 2.34, p 23), when it states that there "is no settled term for this value: some speak of 'fraternity', others of 'solidarity'. We prefer the term 'community', which is the value of belonging to a society in which each person's welfare, and that of the whole community, matters to everyone. This value is central in the justification of both the goal of reducing health inequalities (paragraphs 2.27–2.28) and the limitation on individual consent when it obstructs important general benefits. Public health often depends on universal programmes which need to be endorsed collectively if they are to be successfully implemented. Although the initial liberal framework supports the promotion of public goods and services, it presents these primarily as ways of promoting individual welfare. Hence, it does not adequately express the shared commitment to collective ends, which is a key ingredient in public support for programmes."
(4) In the case study on infectious diseases (NCoB 2007: 4.53, p69), in connection to the patents on pharmaceutical remedies: "This raises issues of considerable complexity about, among other things, intellectual property, global solidarity, and appropriate mechanisms and criteria for the fair and equitable sharing of vaccines and other benefits."
(5) When (4.67, p75) it comments on a Resolution of the World Health Assembly promoting the access of developing countries to influenza vaccines: "One suggestion that has been made is that developed countries should make commitments to supply sufficient doses for healthcare and other key workers in developing countries, or alternatively that WHO receive additional resources to establish contracts for production of vaccine for developing countries. However, global solidarity might be seriously tested even in such a relatively straightforward case, given that the supply of vaccines to developing countries would result in less access for people in developed countries."
(6) When, it summarises (NCoB 2007: p161) the ethical principles that have influenced the document: "In the consultation paper we discussed the concepts of autonomy, solidarity, fair reciprocity, the harm principle, consent and trust, and asked which might be considered more important, and whether these could be ordered into a hierarchy. Although some respondents thought one or several of the principles to be more important, there was no consensus over which these should be. Some respondents considered that these were all important, some suggested other principles, including beneficence, justice, honesty and responsibility, and a few suggested that the 'four principles of biomedical ethics' should be used instead."

particularly helpful for the reinterpretation of core biological concepts such as autonomy and justice (see also Dean 1996).

b Relational Autonomy: Baylis and colleagues (2008: 201-202) emphasise that autonomy remains an important concept in the context of a relational approach to public health ethics:

> "it is essential to demonstrate that the interests of the group truly do outweigh the values of the individual whenever policy seems to require violations of individual autonomy. If there is a way of achieving the desired outcome without sacrificing autonomy interests, public health policy makers need to investigate these options."

According to the authors, the main difference between their approach and other conceptualisations of the role of autonomy in healthcare is not the importance that they attribute to it, but its definition. Baylis and colleagues argue "that the notion of autonomy to be used in such discussions [can] be understood relationally rather than in its traditional individualistic formulation" (Baylis et al. 2008: 202; see also Shalev 2010; Sherwin 1998):

> "Rather than pretending that individuals can make decisions 'free' of outside influences, relational autonomy encourages us to pay close attention to the types of forces that may shape an individual's decisions. […] As such, autonomy is a product of social relations (rather than a purely individual achievement)" (Baylis et al. 2008: 202).

Social justice comes in as an important factor in this context as "the choices that individual persons can make depend fundamentally on the options available to them" (Baylis et al. 2008: 202). The authors then go on to operationalise this in a rather formulaic way, focusing on how different policy decisions narrow down or broaden the options available for any given individual.

c Social justice: The main forms of justice relevant in the field of public health are social justice and distributive justice (see also Young 1990; Powers & Faden 2006[30]). Baylis et al. (2008: 203) regard as particularly relevant for relational approaches to public health ethics the definition of Powers and Faden (2006: 15). Powers and Faden see social justice as being "concerned with human well-being". The implication of this for public health ethics is that "particular attention must be paid to identifying and unravelling complex webs of privilege and disadvantage" (Baylis et al. 2008: 203). This raises the question of how such generic notions can be operationalised for ethical analysis and policy.

d Relational Solidarity: Many authors (e.g. Childress et al. 2002; Singer et al. 2003; Tauber 2002) suggest the inclusion of solidarity as a point of reference in public health ethics. Baylis et al. (2008: 204) agree with this objective, yet they contend that a further theorisation of the term is necessary before solidarity can be employed in a fruitful manner. They critique that with "conventional solidarity, the 'us' are persons with a common identity, perhaps forged through a common struggle or endeavour. In neither instance does solidarity reach beyond intimate or communal bonds to capture distant strangers, many of whom may be among the vulnerable and systematically disadvantaged members of society" (Baylis et al. 2008: 204). This criticism, however, reflects a one-sided reception of the literature on solidarity, as reflections on this very question – how solidarity can be employed to extend its effect to people who are different and distant from us – range from early Christian writings to recent feminist and political conceptualisations of solidarity (see Chapter 2). Baylis and colleagues' critique in this regard is even more puzzling as they explicitly refer to some of the scholars who have elaborated the very question that Baylis and colleagues claim has been neglected: in particular, Jodi Dean's (1996) notion of reflective, and Houtepen and Ter Meulen's (2000b)

[30] Young (1990) employs a different definition from Powers and Faden (2006) yet Baylis et al. (2008: 203) consider these complementary rather than conflicting.

reflexive solidarity (again, see Chapter 2). It remains unclear in Baylis and colleagues' account who the proponents of "conventional solidarity" are that they seek to overcome.

Public health ethics and solidarity: a strong place for (strong) government?

3.26 The relationship between state and individual is particularly central to a number of approaches to public health that invoke solidarity. Marc Roberts and Michael Reich (2002: 1057) state that the foundational conviction of public health is that

> "health is generally viewed as special or different from most other things produced by the economy. In this view, health is a component of each citizen's opportunity – like basic liberties as free speech and political participation. This positive-rights perspective makes government responsible for a minimum quality and quantity of life for all, and to provide the health care needed to guarantee that minimum."

3.27 Similarly, Søren Holm (n.d. 12-13) argues that health should be seen a public good, like

> "clean air, effective national defence and street lighting. Economic theory predicts that there will be undersupply of public goods because their non-excludable nature means that it will be impossible to extract market value payment from all consumers of the goods. This entails that there is an economic argument for state intervention in the market and possible state provision of the good or taxation to make up for the market failure."

3.28 The entry on 'Public Health Ethics' in the *Stanford Encyclopedia of Philosophy* (2010a) highlights that "collective interventions in service of population health involve or require government action". The intimate link between government action and public health, however, can also be explained by the requirement of efficacy: "In many public health contexts, the only feasible or acceptably efficient way to implement a policy affects the entire population, leaving no or only very burdensome options open to individual non-cooperation". In other words, only a system with enforceable sanctions in place can avoid the 'free rider' problem.

3.29 These understandings offer slightly different explanations for public health's intimate link with state authority. What they have in common, however, is that they understand solidarity as people's inherent need to mutually assist each other (including those whom they do not know in person but who are part of the same political territory and jurisdiction), and that they see such solidarity as a factor that both justifies the prerogative of state authority over individual autonomy, as well as mitigates its effects (see also Jennings 2007). In other words, because people have an inherent need for assistance – both to give it and to receive it – we need state authority; which is of course the core argument of social contract theories. What these authors add to classical social contract theory is the explicit reference to solidarity as the practice and value that accounts for, and describes, the human need for assistance. Solidarity, here, assumes the role of not a legal[31] but a *sociological* reason and justification for (a) the existence of legal arrangements that per definition curtail the "natural freedom" (Rousseau) of people; for (b) the existence of *specific configurations* of legal arrangements that exist in a given context; and for (c) the efficacy of such legal arrangements. We regularly observe legal norms not only because we are afraid of the consequences if we do otherwise, but also because we believe in the benefit of such norm observance.[32]

3.30 Alternative approaches can be found in the work of Amartya Sen, for example, in which he sees health not as a prerequisite, but the result, of individual choice (Sen 1999; see also Sen et al. 2004). This has profound implications for the legitimate role of the state, and for the role of solidarity in relation to the emergence, justification, and observance of legal norms in this context. Although Sen sees the state as playing an indispensible role in providing and actively protecting the conditions for people to lead a healthy life, he would see the role of the state in

[31] As an example for a legal justification for such arrangements, see Kelsen's Basic Norm concept (Kelsen 1967).

[32] The desire of many people to do good – in other words, the interwovenness of the desire to be loved and be lovely (c.f. Craig 2011) – which is inherent in many people's subjectivity and self-understanding, remains under-conceptualised in contemporary bioethics (see Chapter 4).

the context of individual health behaviour (e.g. incentivising and penalising particular behaviours) as more limited than other authors. Solidarity, then, is merely a characteristic of *some* groups and collective entities with stronger social cohesion and more voluntary (not contractual) mutual assistance within the group.

3.31 Apart from the question of what one's particular view is on the legitimacy of a strong state in the context of public health – and the role of the state in helping to institutionalise and to enforce solidaristic arrangements – it is apparent that public health lends itself more strongly than other disciplines to conceptualising dynamics and mechanisms of social cohesion and reciprocity because it is concerned with the health of populations rather than individuals.

3.5 Context 2: Solidarity and healthcare systems

3.32 In the European literature, one of the contexts in which solidarity has been most explicitly invoked is the institutionalisation of health and social care, and welfare state concepts more generally. As Ine Van Hoyweghen and Klasien Horstman (2010: 344) state, "solidarity has been understood as a central mechanism and principle for compensation in European welfare states since the nineteenth century" (see also Schmidt 2008a).

3.33 This understanding of solidarity, which underpins the welfare state and public health care systems, is the point of departure for Ter Meulen. et al. (2010) as well. Yet their book *Solidarity in Health and Social Care* in Europe, one of the few books specifically devoted to the issue, starts with a bleak diagnosis: "The welfare state and its solidaristic arrangements of health and social care", the authors argue, "have already been under strain" for several decades. "There is an increasing uncertainty", they continue, "about whether solidarity still is or can be a guiding principle in the shaping of care arrangements within welfare states in the decades to come" (Ter Meulen et al. 2010: 1-2).

3.34 Ter Meulen and colleagues see welfare states in their current configuration as articulations of values that are particularly strongly pronounced in Europe, namely equity and solidarity. Instead of suggesting a narrow definition of solidarity which pertains to a discussion of welfare states and arrangements in particular, they propose an open approach to understanding solidarity as something that is "associated with mutual respect, personal support and commitment to a common cause" (Ter Meulen et al. 2010: 1). The authors then discuss main challenges faced by welfare societies in Europe. Besides demographic and societal changes (such as changes in family size and structure), it is the increasing individualisation of responsibility for health,[33] in conjunction with the individualisation of society more generally, which partly account for the crisis that the welfare state and its solidaristic arrangements find themselves in (Ter Meulen et al. 2010: 3-6). Against this backdrop, Schuyt (1995) speaks of a new type of welfare state, the

[33] The individualisation of responsibility for health has been noted by others, and in other areas, for example by Nikolas Rose 1996, 1999, and 2006. Particularly in his book *The Politics of Life Itself* (2006), Rose foregrounds the increasing individualisation of responsibility for health. He argues that the decisive novelty in contemporary biomedicine is not the accelerating technological advance, or the idea of human enhancement, but instead the increasing individualisation of responsibility. In advanced liberal democracies, Rose holds that it is typically no longer primarily the state which ought to 'improve' people (e.g. by introducing compulsory education, or sterilising the morally and mentally 'abnormal'). In contemporary biomedicine, individuals are increasingly being called upon – and calling upon themselves – to 'enhance' themselves. Rose is one of the few authors who goes beyond merely claiming that responsibility is increasingly individualised but who also conceptualises this process. Rose does this by linking it to changing modes of government (and governance respectively). The regulatory technologies we encounter today, he argues, "do not have their origin or principle of intelligibility in 'the state', but nonetheless have made it possible to govern in an 'advanced liberal' way, providing a plethora of indirect mechanisms that can translate the goals of political, social, and economic authorities into the choices and commitments of individuals" (Rose 1996: 165). Hence, governmental technologies that devolve responsibilities and burdens to and on individuals, find their complement in modes of individual self-regulation. Rose's is thus an important contribution that significantly complicates the at times rather simplistic discussion of individual autonomy vs. collective interest, by reminding us that the collective is always part of the individual and the individual is always part of the collective. For views in support of the increasing indivualisation of responsibility in the context of health, see Anand et al. 2004, and in particular, Wikler 2004.

prime task of which is no longer to care for all of its citizens, but instead to enable them to care for themselves.

3.35 Although every welfare state contains some solidaristic elements, the common understanding is that the larger the extent to which any given system re-distributes resources among the members of the collective, the more it is an articulation of solidarity. Bonnie et al. (2010: 784) discuss three types of solidarity in the context of health and social care insurance in particular:

a *Risk solidarity* is expressed in arrangements that insure everyone under the same conditions, independent of their actual risks. These risks can be known, such as a pre-existing disease; they can be undetermined, such as in the absence of a genetic test for Huntington's Disease in the context of family members suffering from the disease; or they can be undeterminable, such as the risk for Alzheimer's Disease, which is undeterminable because we do not (yet) have adequate knowledge about what causes the disease.

b *Income solidarity* is expressed in arrangements where those with higher incomes pay more and thereby subsidise the care for those with lower incomes.

c *Lifestyle solidarity* is a more recent term that has been used to signify arrangements that offer insurance under the same conditions to those who engage in high risk lifestyles as to those with low risk lifestyles (Trappenburg 2000).

3.36 So far, explicit discussions of risk solidarity have been mainly restricted to the Netherlands (see also Van der Made et al. 2010: 230; Tinghög et al. 2010). But discussions about whom to charge higher premiums within – or to exclude entirely from – solidaristic arrangements have taken place in many other countries in Europe and North America. We examine these questions in more detail in the case study on lifestyle-related diseases in the context of the NHS.

3.6 Context 3: Solidarity and global health

3.37 As Verkerk and Lindemann (2010: 92) argue, in this day and age "it is impossible for bioethicists to ignore the international dimensions of their field" (see also Widdows 2011; Santoro 2009; Holm & William-Jones 2006; Ruger 2006; Glasner & Rothman 2001; Barry 2001). Verkerk and Lindemann refer to four different readings of globalisation which are relevant in bioethics. Firstly, one where globalisation is a normative goal of focusing on global issues, instead of the dyadic doctor-patient relationship or medical technologies (e.g. Daniels 2008); secondly, as the attempt to "develop a universal ethical theory that can transcend cultural differences" (Verkerk & Lindemann 2010: 93; Abdallah et al. 2003); thirdly, as an awareness of the proliferation of bioethics across the globe (Hellsten 2008; Ausilio 2006);[34] and fourthly, as "a concern to avoid cultural imperialism" (Verkerk & Lindemann 2010: 93), which is put forward very strongly also by feminist bioethicists. Verkerk and Lindemann themselves highlight the importance of each one of these readings, but argue for an even more radical reassessment of some of the core underpinnings of bioethics as we know it. Like many others, they hold that the central role of autonomy needs to be reassessed, but the analysis, so they state, should not stop there. They call for the practice of bioethicists including a level of critical reflection. Although the term solidarity does not feature explicitly in their argument, it is apparent that Verkerk's and Lindemann's critique targets the implicit hierarchies inherent in cross-cultural and global bioethics discourses and seeks to replace these hierarchies by mutual assistance between equals. They call for more justice of resource sharing on a global scale, and in the relationship between and within generations (Verkerk & Lindemann 2010: 95).

3.38 Gostin et al. (2010) endorse a similar understanding of mutual assistance between countries motivated by a sense of shared duty, which they take to be distinctly different from charity:

[34] This latter reading is different from arguments that ethical frameworks (and regulatory frameworks implementing or institutionalising ethical norms respectively) must be global in order to be effective; see e.g. Widdows (2011).

> "Framing global health funding as 'aid' is fundamentally flawed because it presupposes an inherently unequal benefactor-dependent relationship. Rather, global collaboration requires a collective response to shared risks and fundamental rights, where all states have mutual responsibilities. 'Charitable giving' usually means that the donor decides how much to give, for what and to whom. Consequently, 'aid' is not predictable, scalable or sustainable. It undermines the host country's 'ownership' of – and responsibility for – health programmes."

It is noteworthy that Gostin et al. (2010), like Verkerk and Lindeman, do not explicitly use the term solidarity; it does not appear even once in their article. Harmon (2006), in contrast, refers explicitly to solidarity when he argues that because of the nature of the ultimate goals, solidarity needs to be manifest in a global context: "[W]e must […] establish institutions with the ability to *enforce* which is *globally* utilitarian and therefore better capable of actively enhancing the health and human dignity of everyone" (Harmon 2006: 233) [original emphases]. Brunkhorst (2005), who is deeply sceptical of the feasibility of a global *gemeinschaft* bound by solidarity, does however believe in the feasibility of a "juridified" global community based upon enforceable basic rights (see also Pensky's [2007] notion of "cosmopolitan solidarity").

3.39 Returning to bioethics more specifically, Darryl Gunson discusses the role of the concept of solidarity in the context of the *Universal Declaration on Bioethics and Human Rights* [UNESCO 2005], which seeks to articulate a consensus on core values in bioethics. Gunson emphasises the great symbolic and political importance of the Declaration, despite its non-binding legal character. Solidarity is mentioned three times in the Declaration, yet it is never defined. The most important instance in which solidarity is mentioned in the Declaration pertains to the "solidarity between and among States, as well as individuals, families, groups and communities, with special regard for those rendered vulnerable by disease or disability or other personal, societal or environmental conditions and those with the most limited resources". It is the task of states to "protect and promote" such solidarity (UNESCO 2005, Art 24). The second context in which solidarity is explicitly mentioned in the Declaration (twice, once in the title and once in the text) is Art 13, which reads as follows: "Article 13 Solidarity and cooperation: Solidarity among human beings and international cooperation towards that end are to be encouraged". Gunson (2009) is sceptical of the possibility to fruitfully employ solidarity in this context if it is used in such a broad and undefined manner.

3.40 Another approach to global solidarity can be found in the work of political philosopher Carol Gould (2007). Gould introduces the term "network solidarity" to signify a form of solidarity across borders. In general, Gould (2010: 2) understands solidarity as having three dimensions: first, referring to "a sense of collective identity and mutual sympathy among members of a single community, most often thought to be national in scope"; second, a network made up of interpersonal and inter-group relationships "feeling empathy with each other and standing ready to give mutual aid to each other to counter oppression or relieve suffering"; and third, "the interconnectedness of people in groups oriented to shared purposes within institutional contexts", where interpersonal relations, or even shared objectives, may not be immediately evident. She considers these three dimensions to be not mutually exclusive but overlapping. Her notion of network solidarity comes close to Scholz's (2008) understanding of political solidarity, which applies to people joining their fate with respect to shared goal and commitment irrespective of national borders. Where Gould's network solidarity differs from Scholz political solidarity, which could manifest itself in a wide transnational movement, is that Gould understands global solidarity as inseparably connected to an emphasis on human rights, while Scholz's approach says little about what the particular goals and commitments in a global context can or should look like. In Gould's view, solidarity is closely linked to the goal of global justice. Solidarity, Gould argues,

> "supports global justice in one of two ways: it can give rise to an awareness of their shared needs and common interests as human beings in a way that underlies global justice notions, or it can establish their unity within a broad transnational association within which redistribution can now be seen to be justified, in view of their interconnections with each other." (Gould 2010: 11)

3.41 In sum, most authors writing about solidarity and global health are concerned with arguing whether or not social cohesion and community is possible across national borders, and if so, how it could be achieved. Although relatively few focus on what substantive values such as global community and solidarity should help to materialise, most assume that a better distribution of resources, and more equal access to healthcare across the globe, would result from global solidarity.

3.7 Context 4: Solidarity as a European value?

3.42 As shown in Chapter 2, the concept of solidarity has a distinctly European heritage in the sense that both its Christian and its socialist legacies emerged from social and historical configurations in Europe from the 18th century onwards. For example, without reference to the inner workings of Catholic orders, the concept of fraternity, which underpins the notion of solidarity in contrast to charity, cannot be understood. But besides its European heritage, is solidarity a distinctly European value today?

3.43 Matti Häyry regards both precaution and solidarity as particularly (continental) European values vis-à-vis the "American 'autonomy and justice' approach, which is often seen as overemphasising the role of individuals as consumers of health services" (Häyry 2005: 199; see also Häyry 2004). Precaution and solidarity, Häyry argues, "embody values that transcend hedonism and egoism" (Häyry 2005: 199; see also Holm 1995). Häyry (2003: 199) even speaks of the image of a "Europe under Siege […] by American values in bioethics" that is constructed by some European bioethicists. However, Häyry (2003: 200) sees this latter critique as "obviously misplaced", as it is *a particular understanding* of the four oft-cited *Principles of Biomedical Ethics*[35] that is American, not the values of autonomy, justice, beneficence, and non-maleficence themselves. He dismisses most of the criticism of the four principles with the exception of the concern "about the missing virtues", which he argues "can point to a genuine theoretical deficiency in the four-principles approach" (it should be noted also that the later editions of *Principles of Biomedical Ethics* contain a chapter dedicated to "virtues").

3.44 Tomasini (2010: 4; see also Daniels 2006; O'Neill 2002b) specifically warns of "spending too much time defining our principles in opposition to the Americans", as this could put Europeans "in danger of looking insecure and creating a 'resistance identity' (Castells 1996) – further legitimising the orthodoxy of the four principles." As particular European values, Tomasini (2010: 5-6) suggests inclusivity and scope, particularity and context, multiplicity and rigor, deep questioning, harmony, consensus and disagreement, and pluralism ("many voices") (see also Hermerén 2008).

3.45 Sass (1992: 367-368) argues that

> "The principle of solidarity is a notion that is not easy for those in the Anglo-American philosophical tradition to understand. A richer notion than either social or legal reciprocity among freely contracting individuals, it is both presupposed by the sphere of self-interested social interaction, because it is a personal virtue, and complementary of that sphere, insofar as it is a principle of social morality, justifying institutions of social justice and welfare."

Less explicitly, yet in a no less relevant manner, is solidarity as a European value discussed in literature on European welfare states. Hinrichs, for example, regards a "culture of solidarity" as the basis for the German welfare state (1995: 653). Hinrichs contends that this culture of solidarity is "vulnerable to political influence" (Hinrichs 1995: 657), yet without specifying by which mechanisms this influence operates. Boßhammer and Kayß (1998: 376) argue that the liberal criticism of state interference

> "in the lives of their citizens through the redistributive measures of social policies […] has provoked a fierce [*sic*] among European philosophers about the moral ideals and legitimate principles underlying

[35] Beauchamp and Childress (2008).

state welfare systems among which the Principle of Solidarity appears to be the crucial and at the same time most controversial."

3.46 Boßhammer and Kayß further hold that

> "[t]oday, poverty and need are viewed as a social problem that is part of the structure of modern capitalist societies themselves. And since it is these societies themselves that creates [*sic*] the problem, it follows that the perpetrators of the problem must pay to mitigate its effects. The call for social solidarity no longer expresses a moral appeal to compassion for fellow citizens, but rather a demand for compensation made by those to whom society has done harm." (Boshammer and Kayß 1998: 382)

3.47 It should be noted here that the understanding of positive rights as a manifestation, or even the main form of materialisation, of solidarity, contrasts with the views of those authors who hold that solidarity exists only when assistance is provided on the basis of other than contractual commitments (see Chapter 2).

3.48 In sum, there seems to be some shared understanding amongst European authors that solidarity is indeed more influential in European discussions than in for example the Anglo-American bioethics discourse. At the same time, however, there is awareness that it should not be set unduly into opposition with other, 'Anglo-American' values. Rather than criticising the focus or value of other areas or systems, some authors call for more engagement of European values such as solidarity. Solidarity, here, is closely linked with welfare society arrangements.

3.8 Criticism of use and application of solidarity

3.49 Most of those writing about solidarity in bioethics in the four contexts we described above do so with a distinctly positive aim regarding solidarity's importance and use. They call for further attention to solidarity when discussing bioethical questions, or even for its protection against threats such as the increasing individualisation within modern (welfare) states. Others are more critical. However, in the bioethical literature, critique of the use of the term solidarity is most commonly targeted at the mobilisation of the concept in order to justify conduct.[36] More frequently than critiquing a particular substantial content, criticism is geared toward the fact that solidarity is mobilised in a particular context at all, as the term is allegedly too vague for this purpose (see e.g. Capaldi 1999). Darryl Gunson, for example, wonders whether solidarity "can and should […] feature in documents such as the Universal Declaration on Bioethics and Human Rights" [UNESCO 2005], as it is unclear whether it is "anything more than a vague notion with multiple possible interpretations" (Gunson 2009: 241).[37]

3.50 To tackle this problem, Gunson develops a definition of the term which he hopes provides "a middle path between the *particularistic* connotations of solidarity and the demand for *universal* applicability of principles that documents such as the [Declaration] make" (Gunson 2009: 243) [original emphases]. He argues that "being connected […] seems to unite the different uses of the term" (Gunson 2009: 245), although he does not consider mere membership to a group as either necessary or sufficient for solidarity (Gunson 2009: 243). For example, solidarity is often expressed with members of a group to which one does not belong:

> "As a way of capturing these points, let us say that solidarity consists in the willingness to take the perspective of others seriously and *to act in support of it*. As a working definition, it captures the 'being connected' that runs through the various historical uses of the term and also the connotations of political engagement through action that academic and ordinary usage seems to imply. It also serves to capture the sense in which solidarity is not just a sentiment as, for example, empathy is." (Gunson 2009: 247, original emphasis)

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[36] Conduct is understood widely in this context as comprising actions and policies or other kinds of moral or legal rules.

[37] Husted (1999) exemplifies the vagueness of the term solidarity with reference to the situation in which both those arguing in favour of and those arguing against the use of genetic information for insurance underwriting base their claims on the notion of solidarity (see also Aarden et al. 2010).

3.51 Gunson (2009: 247) argues that if examples of solidarity are always connected to a particular substantive normative cause or objective, then the promotion of solidarity becomes a particularistic endeavour which undermines any claims to universality (for a critical perspective on this contention see Gould 2010). If, on the other hand, solidarity was seen as a universal value, it would still be different from other values claiming universal applicability in political and international declarations:

> "Whereas it seems to make sense that one should respect human dignity or individual autonomy, perhaps unconditionally, the same cannot be said of a similar order to 'be solidaristic'. The reason for this is simply that it only makes sense in the context of a commitment to *specific* political causes. We need to know with whom and about what before we are in a position to evaluate whether causes are worthy of allegiance." (Gunson 2009: 247; original emphasis)

3.52 This understanding of solidarity of a value that is necessarily specific, if not particularistic, is what Gunson refers to as "strong" solidarity. He contrasts this with what he calls a "weak" understanding of solidarity which "does not demand that one act in support of a goal or political cause" but "consists in *the willingness to take the perspective of other seriously*" (Gunson 2009: 247, original emphasis; this comes very close to Jodi Dean's concept of reflective solidarity; see above where we discuss Dean's work). Such a "weak" concept of solidarity, Gunson argues,

> "has an important role to play in universal declarations as promoting it is to foster the context from which social understandings and motivations for justice, necessary for healthy democracies, can emerge. With this understanding of solidarity in play, we can see that the [Declaration], despite only *explicitly* mentioning the concept a handful of times, is a document that is already *implicitly* solidaristic" (Gunson 2009: 243, original emphases).

3.53 Another example of the rare instances in which the use or meaning of solidarity is challenged explicitly in bioethical writings is the work of Klaus Peter Rippe. Rippe (1998) distinguishes two meanings of solidarity from each other: The first is solidarity of the kind that is "found in the family, in the neighbourhood, in the village, in clubs and guilds. In these instances, assistance and willingness to assist, arise from special interpersonal relationships and ties" (Rippe 1998: 357; see also Scholz's [2008: 21] concept of "social solidarity", which pertains to group cohesiveness). The second kind of solidarity is what Rippe calls "project-related solidarity" – pertaining to the willingness of people without direct interpersonal relations to provide assistance to others to reach certain shared goals (Rippe 1998: 356-357[38]). In the second group of cases, solidarity is characterised by the absence of immediate personal relations or even acquaintance:

> "the solidarity with children afflicted by cancer […], with Salman Rushdie, or with the hunger strikers in Bischoferrode in Thuringia. If those in need of help and those providing help actually ever meet, it is only as a result of the solidarity shown and not the *reason* for the solidarity"[39] (Rippe 1998: 357) [original emphasis].

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[38] This approach overlaps significantly with Scholz's (2008: 33) concept of political solidarity; which 'highlights individual conscience, commitment, group responsibility, and collective action'. In addition to social and political solidarity, Scholz's (2008: 27) typology also includes 'civic solidarity', which she associates with "more recent developments in the use and analysis of the term". It refers to the "relationship between citizens within a political state" and is therefore distinct from political solidarity, which can comprise cohesion between people united by a common political commitment and conviction, regardless of their 'categorical identity' deriving from nation or territory (Calhoun 2002). It is, however, more than mere national identity insofar it entails a particular relationship between citizens not only among each other but with the state: "Civic solidarity, then, is the idea that society has an obligation to protect its members through programs that ensure that adequate basic needs are met" (Scholz 2008: 29).

[39] Rabinow's (1992, 1996) concept of biosociality is instructive here. In the early 1990s, Rabinow argued that in the future, biological characteristics would constitute new groups. Rabinow highlighted particularly groups emerging around shared genetic characteristics, but the applicability of the biosociality concept is by no means restricted to such scenarios. It is no coincidence that Rabinow's thoughts on biosociality were influenced by Thomas Mann's *The Magic Mountain* (1924), where a collective identity emerges among people who are united by similar ailments (and arguably by their spending prolonged periods of time in a remote mountain resort in the Alps) (see also Gibbon & Novas 2007).

3.54 This second meaning of solidarity is where Rippe's explicit criticism comes in. He calls this second concept of solidarity not only "too vague, not permitting a distinction between charity and solidarity" (Rippe 1998: 357), but also as "theoretically unfruitful and even misleading". He thus proposes to abandon the term "in order to regain sight of the individual phenomena". This could be read as a welcome reminder to refrain from using the label of solidarity in a formulaic manner, which tempts to forego an analysis of the particular reasons for, and the particular forms of articulation of, solidarity in concrete cases.[40] It is important to note that Rippe's criticism does not stem from a pessimistic view regarding waning social cohesion in contemporary societies, nor is it merely a comment on the increasing individualisation and atomisation of societies (e.g. Baylis et al. 2008; for a summary see Houtepen and Ter Meulen 2000a: 333[41]). Instead, his argument is targeted at the analytical value of the concept. Rippe contends "that modern societies are perfectly capable of inspiring feelings of loyalty and civic virtues, though not by resorting to the old sources of "solidarity". Modern forms such as free associations, participation and, not least, the existence of a liberal society itself are sufficient" (Rippe 1998: 355). Referring to alternative terms such as "trust", Rippe argues, does not solve the problem either, as this "only repeats the same mistake" (Rippe 1998: 363). 'Social capital' (Coleman 1990; Putnam 1993, 1995, 2000; see also Chapter 4 on social capital) would be a better fitting term. Yet the best way of referring to what is often called solidarity is, in Rippe's view, to be specific enough to say exactly what we mean.

3.55 Sally Scholz (2008) states that not only in bioethics but more broadly in the field of political philosophy and social theory, the "primary objection to solidarity – in whatever its form – is that it is anti-individualistic." She refers to the work of Nicholas Capaldi, who argues that

> "the concept of solidarity confuses or equates the genetic contention that we necessarily derive our identity from a communal context with the definitional contention that we are identical with the context from which we originate. It fails, in short, to capture the evolving senses of community within liberal culture" (Capaldi 1999: 39).

This portrayal, of course, draws a caricature of relationist approaches (see above where we discuss Baylis et al.) which mostly do not *equate* people with their communal context but instead argue that this context needs to be taken into consideration as something that is co-constitutive of selves and identities. Capaldi's line that "those who advocate the concept of solidarity are unwittingly promoting economic and political policies that (a) inhibit the attempts on the part of many to rise out of their culture of poverty and embrace autonomy and (b) undermine liberal culture" (1999: 39)[42] does not only show that his reasoning is based on a category mistake but it also exposes the undisclosed ideological content of his own argument.[43]

3.9 Main findings and conclusions

3.56 A number of conclusions can be drawn from our literature analysis across most of the bioethical writings examined.

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[40] Rippe explains that solidarity should not be used as a catch-all term because "social ties and relationships within a family [are] of a completely different nature than those between neighbours, compatriots, or members of free associations. This is reason enough to doubt whether the same word "solidarity" should be used to refer to all these different relationships" (Rippe 1998: 363).

[41] However these authors are also critical of the individualisation and 'atomisation' argument. They argue: "To assess whether individualization is a threat to society, the focus on more or less collectivity is misguided and insufficient. The proper criterion is whether personal ties and institutional arrangements are shaped in such a way that participants experience these as part of a common project that they can personally influence to some degree" (Houtepen and Ter Meulen 2000a: 337). Silver (1994: 533) refers to participatory governance as a potential bridge between traditions of solidarity in Europe and the rise of individualism.

[42] See also Heyd 2007, who makes a similar argument as Capaldi does when he criticises solidarity as being anti-individualistic in connection with global justice.

[43] Capaldi's (1999: 39) argument becomes fully circular when he claims that "solidarity is a negative concept" and defines it in contrast to liberalism. He then goes on to say that solidarity is to be rejected because it opposes liberalism.

i. Explicit references to solidarity in bioethical writings are relatively scarce. Solidarity has so far not been a major topic of discussion in the most frequently used textbooks and compendia of bioethics.

ii. Despite the overall scarcity of mentions, uses of solidarity have increased over the last few decades. This increase is linked to emerging discussions of topics that focus on social and collective issues and therefore have need of language that captures the challenges beyond inter-individual relationships.

iii. There is no coherent way in which the term solidarity is used in bioethics. Most explicit uses of solidarity fall into one of two categories: (i) descriptive: referring to the 'fact' of social cohesion within a particular group; or (ii) prescriptive: calling for more social cohesion within a group. If the meaning of the term is taken to be descriptive, namely as describing an empirical fact – i.e. that particular people are tied together by bonds of mutual assistance, shared goals, and/or other aspects of a situation that they share (a shared 'fate') – then solidarity is a precondition for all social and political life. If the term is used in a prescriptive manner, so that it e.g. normatively calls for mutual support within a specific group of people, or for more social cohesion in society as a whole, then the assessment of the value and importance of solidarity takes on a political form. This can lead to a lack of reasoned justification and argument: invoking solidarity sometimes appears to take the place of offering a more careful analysis of e.g. benefits and costs and other relevant factors that should be considered in the justification for a particular course of action or policy.[44]

iv. Solidarity is much more prominent in bioethical writings than the frequency of explicit uses of the term would suggest. There is a discrepancy between the number and scope of discussions in which the term solidarity is employed explicitly, and discussions where situations, norms, and dilemmas which are associated with solidarity by some authors and not by others appear in the literature. This mixture of implicit and explicit uses leads to the term being, in general, underdetermined in much of the debate. Unless authors give an explicit account of their particular use of solidarity, the concept is more often employed as a label for a number of differing lines of argument. In addition, synonymous use of related terms is widespread, which might lead to confusion (see Chapter 4). Some have therefore suggested that as a concept, solidarity is necessarily vague. However, based on our analysis, solidarity is not a vague, that is, an undefined or indefinable, term. Rather, it is a complex and multi-layered concept that lends itself to being defined with several nuances in meaning..

v. There is great variety regarding the scope of the group that solidarity applies to, ranging from solidarity within a family to solidarity with all people in the world. At the same time, there is very little literature within bioethics that discusses empirically or conceptually how group identities and senses of belonging emerge.

vi. The value that solidarity is most frequently associated with or even equated to is social cohesion. Only few contributions (mainly in connection with welfare systems and global health) explicate substantive values that solidarity is seen to effectuate (e.g. global justice; fair distribution of scarce resources).

vii. Explicit references gravitate around four topical foci, namely public health, justice and equity of healthcare systems, global health, and solidarity as a European value.

viii. Apart from those criticising the alleged vagueness of the term, criticism revolves around solidarity as being anti-individualistic. This is due to the fact that it is taken to be always based on particular, substantive ideas and values (in this sense critique of solidarity overlaps significantly with the main points of critique of communitarian thinking).

3.57 In addition to these main findings, which were drawn from direct reference to the body of works examined, there is also an overarching observation which emerges not only from the sum of bioethics academic publications, but also from reading – less systematically – non-academic sources, and from the verbal input we have had during our workshops.

3.58 In societies with a high density of formal or informal solidaristic institutions (traditions of volunteering; strong welfare states etc.) solidarity seems to be engrained in society to such a large extent that it does not need to be affirmed by making it explicit. It is only when solidaristic arrangements are seen as coming under threat – such as in the case of the NHS in the UK, or of social welfare arrangements in other European countries (Ter Meulen et al. 2010) – that reflections on solidarity and what it means become more visible. Thus, threats to solidarity seem to strengthen attention to solidarity exactly at a time when solidarity itself seems to disappear. This seems to be the case in public discourse, as well as in policy documents and academic writing.

3.59 There can be many reasons for why solidarity is threatened; economic crises or natural disasters are among them. While economic crises in particular can lead to political discourses focussing on individual responsibility and collective sacrifice – which are often barely concealed arguments in favour of a breaking off of solidaristic arrangements – crises can also have the effect of enhancing social cohesion. Economist John Roemer, for example, talks about the solidarity-generating potential of crises. In times of economic crises, Roemer argues (2009: 3), solidarity can be expected to gain currency, because "crises tend to homogenize the risk exposures of the working and middle classes", who then form a sufficiently large majority to institutionalise solidaristic arrangements even against pressure from the most privileged.[45] While Roemer's statement applies mostly to economic crises, natural catastrophes or particular health threats can also be seen as homogenising risk exposures across a probably even wider range of societal groups. In this light, Van Hoyweghen's suggestion that people's awareness of the "fact that we are all susceptible to genetic diseases" (2010: 437) fosters solidarity, for example, could be seen as explaining why solidarity has featured in some discussions about genetics and risk (see Chapter 6 on biobanks). The NCoB (2009), in its report on dementia, puts forward a similar argument where it argues that within a society or country solidarity often comes to the fore at times of stress such as war or natural disaster. The high prevalence of dementia, and the fact that we all face a significant risk of developing dementia as we get older, might enable us to develop a particular sense of solidarity with each other in the context of dementia care. (NCoB 2009: 29).

3.60 On the other hand, Schuyt (1995: 303), drawing upon Dahrendorf's work on anomia (Dahrendorf 1985), states that "[o]ne of the current paradoxes in Western societies is that there has been a revival of a highly individualistic, achievement-oriented ethic in a period during which there is a high structural unemployment due to non-individualistic causes".

3.61 How can the solidarity-enhancing potential of crises diagnosed by some authors be squared with the observation by others that crises tend to decrease and destroy solidarity? If it is true that solidarity becomes most visible when under attack, why are there so few mentions overall? With regards to the field of bioethics specifically, the diagnosis that the crises of recent years have increased the currency of solidarity stand in seeming contrast with the overall low visibility of solidarity in recent bioethical writings – at least in terms of explicit references and discussions. In 1998, Bayertz contended that "the moral and political philosophy of our times has avoided the concept and problems of solidarity" (Bayertz 1998: 293). The extent to which

[45] We take up this issue again in Chapter 5, where we develop a working definition of solidarity that we believe bridges the descriptive and prescriptive understandings of the term.

[45] Kevin Waldby and Aaron Doyle (2009) argue that the individualisation argument (i.e. the idea that communal bonds are dissolving) in the risk society concept ignores the point that risk does not only individualise but also promotes solidarity, for the same reasons as Roemer (2009) puts forward. See also Hawdon et al. (2010).

"modern moral philosophy was founded on the idea and ideal of individuality", Bayertz (1998: 294), argues, is responsible for this problem.

3.62 As Ashcroft et al. (2000: 394) note, solidarity "as an element of political discourse" in the UK made its appearance only in the late 1990, in connection with Tony Blair's 'New Labour' and the 'Third Way' debate.[46] Ashcroft et al. (2000: 394) consider the work of Anthony Giddens – one of the main theorists behind the Third Way movement – as particularly helpful in understanding the "history and pre-history of the debate on solidarity in the UK". Ter Meulen and colleagues (2010: 7) refer to the somewhat problematic character of the solidarity concept:

> "It is not accidental that appeals to solidarity are commonly made at times and in circumstances that its basic prerequisites are seemingly threatened. The invocation of the importance of community ties is historically related to the processes of modernisation that were perceived to undermine such ties. An explicit appeal to solidarity usually denotes that the strength or legitimacy of a certain community or the motivation for its members is in some sense problematic. In a flourishing community, appeals to solidarity ought to be superfluous."

Thus, perhaps it is indeed the case that a 'solidarity inversion' exists – the more solidaristic we are, the less we talk about it. This view would also be entirely compatible with a view of persons whose identities, interests, and needs are to a large extent shaped by their relations to others. This, in turn, is the starting point for our own understanding of solidarity, which we will outline in Chapter 5.

[46] Solidarity was an evident counter-value to Thatcher's New Right politics and policy; her statement that 'there is no such thing as society, only individuals and their families' rejects the very reference points of solidarity in the tradition of social democratic and also Christian movements (Stjernø 2005), namely, a larger group than one's immediate family environment that one can feel responsible for, and attached to.

Chapter 4

Related terms

Chapter 4 – Related terms

4.1 One of the difficulties when analysing solidarity is that there are a number of related concepts that in some of the literature are used almost synonymously. For example, altruism and solidarity are sometimes taken to mean the same (for example, in the discussion revolving around modes of exchange and sharing, as specified in Titmuss' "gift relationship" [1970], these modes of exchange are described as altruistic, which is then taken to mean that they are therefore solidaristic). This contributes to the perception expressed by some authors that solidarity is a vague term and that it is not possible to distinguish it from related terms, nor to come up with a clear definition of its core meaning.

4.2 We believe that solidarity can be clearly defined and attempt to do so, based on our analysis of the recent bioethics literature, in the following chapter. In order to provide such a clearer understanding of solidarity, in this chapter, we try to distinguish some of the features of important related concepts. We try to offer a – necessarily brief – description of their core meaning, of their relationship with solidarity and of overlaps with other terms in order to prepare for formulating our working definition of solidarity.

4.3 The list of terms described here cannot be exhaustive. Instead, we have chosen those terms that are mentioned most frequently as related to, (partly) overlapping with or synonymous to solidarity in the literature. A few more related concepts will be mentioned briefly when developing our working definition (see next chapter).

4.1 Responsibility

4.4 Very generally, responsibility refers to actors being accountable for an act or an omission of an act. This accountability can be moral, legal, or social (often these dimensions overlap). While legal responsibility refers to duties to act, or to refrain from acting, based on contractual or other legal norms, moral responsibility refers to an actor's obligations in certain situations which go beyond those which are determined by law. Social responsibility takes social norms and conventions of the good as its central point of reference for what is expected from an actor in a given situation; often moral or ethical values are used to justify these social norms. Responsibility is articulated not only in responsible (moral and accountable) behaviour but also in expectations of such behaviour.

4.5 Furthermore, the notion of responsibility is closely linked to the possibility of consequences that the actor perceives as negative in case she does not act responsibly. Nevertheless, as Jeanette Kennett summarises, a person is responsible for her actions only insofar as "she possesses certain characteristics or capacities essential for responsible agency and is in a condition to exercise those capacities in the circumstances (or to determine the condition she is in)" (Kennett 2007: 108; see also Korsgaard 1992) – this means that expectations and norms of responsibilities are typically unequally distributed in a given group.

4.6 The link between responsibility and possible consequences or sanctions is the main difference between responsibility and solidarity. Both can apply to individuals and collectives, but solidarity usually does not necessarily entail or require the penalisation of those who are unsolidary (unless solidarity is articulated in contractual or other legal arrangements; or in cases where unsolidary behaviour is penalised by social stigma). In other words, accountability is configured differently in the context of solidarity than it is in the context of responsibility.

4.7 The concept of responsibility plays an important role in contemporary medicine and bioethics in several respects. First, in the context of the increasing individualisation of the responsibility for health and disease, which is also discussed extensively in connection with designs of health and social care; second, in connection with the responsibility of the more privileged for the vulnerable, in our own societies, and in the context of global health; and third, on a more general level as individual and collective moral and legal responsibility for proper professional and human conduct.

4.2 Charity

4.8 The term charity is derived from the Latin *caritas*, meaning high esteem, preciousness, or dearness. In Christian theology, *caritas* became the standard translation of the Greek term *agape*, signifying the ability of people to love other entities than themselves – that is, their fellow human beings, but also God – in an absolute way. This notion of loving in an absolute way connotes the willingness to accept sacrifices for the sake of these other entities. The expression of the absolute love of God was the submission to religious rules, while the love of others articulated itself in giving and caring, without demanding or expecting anything in return (thus the term 'charitable giving').

4.9 While the term charity itself does not play a big role in contemporary bioethical writings outside of the work of Christian (bio)ethics, the notion of giving or helping without expecting anything in return is mobilised in many instances. It is often portrayed as emerging out of a sense of moral obligation or responsibility, although it is a characteristic of charity that it can never be legally enforced. Charity is a manifestation of altruism, but the two terms are not synonymous. Charity always assumes an asymmetric, top-down interaction, where the – overall – more privileged party gives to the – overall – less privileged party, while altruism does not. Altruism can entail a situation where the person who has very little gives to another one who has a lot; e.g. an organ, hospitality, or human assistance. These scenarios would not typically be subsumed under charitable giving.

4.10 For the same reason, charity is not synonymous with solidarity, although the two concepts are sometimes employed in the exact same manner. They are sometimes both used to signify the objective or willingness to accept costs (financial, emotional, or otherwise) that are incurred by improving the situation of others. However, charity is associated with voluntary giving of the richer and more privileged to the poorer and more needing without the latter having any political or legal claims to it. As laid out further below, solidarity, in contrast, is regularly described as taking the form of institutionalising accepted moral claims of groups in need (e.g. those who need blood donations, organs, or better access to healthcare) as *de facto* or *de iure* rights. In other words, solidarity assumes symmetry in the respect which is relevant for constituting solidarity (e.g. because we both have the same disease I feel solidary with you; or because we are both women. There is no hierarchy between us in this respect, although there may be asymmetries between us in many other respects, such as in how rich or poor we are). The notions of symmetry and asymmetry remain mostly implicit in references to both charity and solidarity in recent bioethical writings.

4.3 Dignity

4.11 Besides its importance in religious doctrine, dignity also played an important role in concepts of inalienable rights inherent in all human beings during and after the Enlightenment. Political theorists and political philosophers have devoted attention to the role of dignity in just/fair societies (e.g. Margalit 1998). Consequently, it also underlies conceptualisations and declarations of human rights, such as the Universal Declaration of Human Rights (UN 1948). Bioethicist Matti Häyry (2003: 203) differentiates between several 'readings' of dignity. First, the Kantian reading, which sees dignity as based on rationality (because humans are capable of reason we have dignity; Würde); second, the Christian reading, which is based on the assumption that dignity results from all human beings having been made in the image of God, and being equal in the eyes of God; third, the understanding that those who carry a human genome deserve dignity (and that nobody may be discriminated because of particularities of her human genome; Kemp & Rentdorff 2009). These readings differ also in their consequences regarding the scope of who deserves human dignity (see also Sass 2001: 220). It is noteworthy in this context that capacity for reason as a precondition has not been discussed in connection with solidarity.

4.12 While dignity could be viewed, depending on its reading, as a potential source of solidarity (I am solidary with you because like me, you have dignity, and in that respect we share sameness), this explicit link has not been put forward in the literature.

4.13 In bioethics, the concept of dignity is relevant also in connection with a possible canon of distinctly European values in bioethics (see Chapter 3). The concept of dignity, Häyry (2003) argues, drawing upon the so-called Barcelona Declaration (Rendtorff & Kemp 2000; Kemp & Rendtorff 2009), plays an important role here, as it captures something that autonomy does not: "some human beings cannot be regarded as autonomous on any reasonable account" (Häyry (2003: 202), yet they still deserve protection. Häyry sees the notion of dignity, in addition to precaution and solidarity, as a meaningful complements to the four principles developed by Beauchamp and Childress.

4.4 Altruism

4.14 As a general term, altruism typically signifies the opposite of selfishness. In this capacity it means a concern for the wellbeing of others (see also Batson 1991 and Haski-Leventhal 2009; for an alternative, rational-choice informed view on altruism see e.g. Schein 1980, as well as utilitarian approaches). In its archetypical form it is different from duty insofar as it is seen as being based on a feeling or sentiment rather than a moral obligation or imperative. In practice, however, the term altruism is used in a much broader way to refer to acts and practices of people to benefit others without: (a) being obliged to do so due to a legal norm, and (b) without receiving, or even expecting, anything in return (the latter property distinguishes it from reciprocity, see below). Altruism is also sometimes used to denote a worldview that is oriented towards a concern for others, rather than being self-centred. However, in other uses of the term, altruism and egocentrism are not mutually exclusive as even the most self-centred person is capable of doing certain things for the benefit of others without expecting anything in return (although she would be expected to do so less frequently than less self-centred people).

4.15 Altruism is different from loyalty insofar as it is more a general outlook and orientation towards others rather than being dependent on a particular relationship to a particular person (e.g. I am loyal to my friend because of the particular friendship we have, and my emotional attachment to her that comes along with it, and not because I am an other-oriented person).

4.16 Altruism cannot be compelled. The main difference in the point of gravity between altruism and solidarity is that altruism focuses on specific relationships between individuals, whereas solidarity goes beyond that and entails practices and values that are located at the collective level (policies, welfare state institutions etc.).

4.17 Matti Häyry (2005: 203) draws an interesting distinction between altruism and solidarity where the former is described in terms of a feeling of individual people, while the latter is a communal commitment or practice. Häyry refers to solidarity as "a distinctly communal form of altruism". For him, altruism – and other human characteristics and sentiments, such as benevolence or sympathy – are not sufficient prompts for us "to do good to specific human beings", because they rely on people actually knowing each other personally. Solidarity, on the other hand, is a communal commitment in which our benevolence affects others to whom we have no personal relation.[47]

4.18 Altruism has been criticised with regards to the binary opposition between either self-interest or other-interest that it implies (see e.g. Buyx 2009). This is also one of the points that have been raised in critique of Titmuss' (1970) seminal work on altruistic blood donation as a 'gift relationship' (e.g. Pinker 2006). As Parry (2008) argues, the assumed dichotomy between altruism and self-interest in Titmuss' work corresponds with the assumption that giving is either

[47] Our own working definition of solidarity – see the next chapter – corresponds with Häyry's understanding of the term with the exception that our definition of solidarity would include acts of giving both by people who do know each other and those who do not know each other in person. The former group would not be excluded in principle.

entirely altruistic or couched in commodification. Also many empirical studies with donors of biological material indicate that giving typically contains both altruistic and self-interested elements, which are inseparable from each other. As Shaw (2007: 293) put it, donors' "moral identities as ethical subjects are created in the donative process."

4.5 Reciprocity

4.19 Reciprocity refers to symmetrical arrangements of giving and receiving. While some lexicons define reciprocity as returning in kind what one has received, the notion of symmetry is more helpful: it means that what one gives and one receives is equal in value (not in kind). The value can be measured in objective terms (e.g. financial currency), or in subjective terms (I give you £2,000 for a signed photograph of Pippa Middleton). Reciprocical arrangements can be immediate (i.e. specific; I give and receive at the same time, or in very close succession; and I receive directly from the person whom I give to); or intermediate (i.e. generalised; I receive from somebody other than the person whom I give to, and/or I receive in a time-delayed manner; for other examples see also Weale 2001; Molm 2010). Most health and social insurance systems contain elements of both immediate (specific) and intermediate (generalised) reciprocity. Examples for arrangements of immediate reciprocity are systems of direct exchange (i.e. most commercial transactions: I give money for a good or service).

4.20 Reciprocity also plays a large role in theories of deliberative democracy, as a key characteristic of communicative rationalities. Reciprocity, here, unfolds not in the exchange of goods in the material sense but in attitudes towards each other, such as openness. In bioethical writings, reciprocity is sometimes mobilised in a similar manner, especially in connection with the values of trust and confidentiality.

4.21 Reciprocal arrangements can manifest themselves in moral, legal, formal, or entirely informal agreements or imperatives. For Weale (2001:70), it is the principle of generalised reciprocity that "is supposed to move our understanding of social relationships from a politics of mutual advantage to more solidaristic forms of social union." Reciprocity is different from altruism, and from solidarity, insofar as altruistic and solidaristic acts do not rely on receiving anything in return (or even do not expect anything in return), while reciprocity does. Reciprocity, mostly in its intermediate (generalised) form, is also one of the most important underpinnings of social capital, which we discuss in the next section.

4.6 Social capital

4.22 In the broader sense, the term of social capital denotes the value of social connections and networks and the ways in which people are invested in communities (by bonds of trust, shared interests, or other associations). Of particular visibility and prominence on the topic of social capital is the work of political scientist Robert Putnam, who defined social capital as "connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them" (Putnam 2000: 19. Putnam credited not himself but several predecessors whose work went back to the early 20th century with having invented the term social capital). Putnam distinguishes between two main kinds of social capital: bonding social capital, which operates within homogenous social groups (within ethnic enclaves, Putnam 2000: 22; it is a "kind of sociological superglue", Putnam 2000: 23), and bridging social capital, which operates within heterogeneous groups (e.g. bowling clubs).

4.23 Like solidarity, social capital "has both an individual and collective aspect" (Putnam 2000: 20). Furthermore, like solidarity, social capital is not beneficial for society by definition: Putnam uses an example of isolated ethnic enclaves to illustrate the effects of some instances of solidarity that are seen as problematic by some. Another example would be performing aggressive – including military – acts against others out of solidarity with a particular group. The main difference between social capital and solidarity is the requirement of reciprocity inherent in social capital, which is not the case for solidarity. As the very term of social capital suggests,

individuals are invested in collectives to benefit their interests (Putnam 2000: 20), and because they trust they will receive something in return. Reflecting several of the definitions of solidarity in the literature and our own as well (see next chapter), in solidaristic arrangements individuals are 'invested' in a common cause on the basis of their recognition that they share something in common with others. From this recognition of sameness emerge shared practices of addressing common problems or working towards common causes (see next chapter). While in solidaristic arrangements reciprocity is often a result, it is typically not a condition.

4.7 Trust

4.24 Trust can be described as a person's reliance on someone or something. It is based on a person's experience and relationship with this other person or entity, which renders actions or characteristics of that latter person or entity predictable to the former person in a relevant respect. For example, we trust that the sun will rise in the morning based on our (individual and collective) experience of this phenomenon. In relations between people, trust often takes the form of 'knowing' that the other person will behave in a certain way that benefits us, or at least does not harm us. We can express trust in respect to a specific context (e.g. I trust him to meet me at the agreed time), or more generally as pertaining to the relationship (e.g. I trust her with my life).

4.25 In the context of bioethics, trust has played an important role in connection with the doctor-patient relationship, and more recently, in the context of biobanking, where it denotes the actual, presumed or desired reliance of participants on the biobank to not harm their interests and pursue communal benefits (see Chapter 6).

4.26 Trust, and trustworthiness, also play important roles in concepts of social capital (see above), where it is seen as the "lubri[cant] of social life" (Putnam 2000: 21). It could be argued that some form of basic trust is a necessary precondition of solidarity. Without the basic trust in the constitutive entity of solidarity – that is, that there is in fact a community or a group of people I share some common fate or features with – it would be difficult to imagine any solidaristic arrangements. However, this is different from the more concrete and direct trust placed in individuals or institutions mentioned before. In these cases, there are specific expectations that something will happen, or will not happen, whereas the basic trust at play in solidarity is more general: reliance on the fact of shared interests, instead of reliance on particular actions (such as some particular benefits) or on omissions of acts (such as some potential harms).

4.27 In sum, despite sharing some elements or overlapping to some extent in meaning, solidarity can most of the time be distinguished from these related terms. The remaining overlap, for example the fact that both charity and solidarity entail the notion of accepting costs to assist others, is not problematic. The terms have different points of gravity. Whenever there is true reason to be unsure about which term applies in a given context, this can be cleared by a careful analysis of the language used, and by striving to be as explicit as possible with regards to the arguments made.

Chapter 5

A new approach to solidarity

Chapter 5 – A new approach to solidarity

5.1 As described in previous chapters, the bioethics literature displays a mixture of implicit and explicit references to solidarity. The concept is also sometimes used as a label for some goal without sufficient explanation, definition and justification, and the synonymous uses of solidarity and related terms are confusing. All this has led some to dismiss solidarity more or less completely because of its allegedly inherent vagueness (e.g. Capaldi 1999, Gunson 1999). Indeed, many different definitions are in use, and solidarity has been called upon to support many – sometimes conflicting – notions. For instance, Jorgen Husted describes that both those in favour and those against the use of genetic information for insurance underwriting in the 1990s based their claims on the concept of solidarity.[48] Similarly, in current debates on whether or not those with 'high-risk lifestyles' should pay higher premiums for health insurance, solidarity is mobilised by both opponents and supporters of lifestyle-stratification (see Chapter 8).[49] It could be argued that such 'vagueness' of the concept of solidarity has benefits, such as a certain level of openness that allows wider ranges of people with different professional and disciplinary backgrounds to contribute to the discussion. However, we believe that such benefits are clearly outweighed by the benefits of a transparent definition of the term involved. In this chapter, we therefore set out a new understanding of solidarity and develop a working definition. We do this on the basis of the analysed bioethical literature and other writings laid out in previous chapters.

5.2 Our aim is not to 're-invent' solidarity; indeed our definition includes many aspects that play a role in various existing approaches. It seeks to set out the elements that need to be made clear and explicit to facilitate a discussion of the consequences of applying solidarity in various contexts. The definition does not seek to provide a 'fixed' definition of the concept. Instead, we hope it can serve as a starting point for future discussions and debate, and can be a tool to facilitate more systematic and perhaps more tangible ways of employing solidarity in bioethical and policy debates.

5.1 Working definition

5.3 In our understanding, and in its most bare-bone form, solidarity signifies **shared practices reflecting a collective commitment to carry 'costs' (financial, social, emotional, or otherwise) to assist others.**

5.4 It is important to note that solidarity is understood here as a *practice* and not merely as an inner sentiment or an abstract value. Solidarity requires actions. Motivations and feelings such as empathy etc. are not sufficient to satisfy this understanding of solidarity, unless they manifest themselves in acts.

5.5 The term 'costs', here, is understood to mean a wide range of contributions that groups or individuals make to assist others. It does not exclude scenarios where groups and individuals involved in such solidarity practices *also* benefit from this involvement. For example, if I sign up to be a bone marrow donor, it could make me feel good about myself and the world; or my neighbour who does a lot of volunteer work could get an award for her contributions. Being rewarded does not retrospectively devalue, or abolish, our enactment of solidarity. Unlike the costs that are carried, such benefits, however – or even the expectation of a benefit or a reward – are *not a precondition* for solidarity.

[48] Husted 1999. See also Rippe 1998, Capaldi 1999.

[49] Those opposing models of lifestyle-risk stratification in the context of health insurance argue that it would compromise the principle of solidarity within a nation if some people were singled out on the basis of behaviours that some claim they should be held accountable for; those supporting such models hold that people choosing to smoke, or to engage in dangerous sports, compromise solidarity by potentially incurring higher costs for the collective (see chapter 8).

5.6 Although solidarity is to be understood primarily as a shared practice (or a cluster of such practices) reflecting a collective commitment, simply claiming that such practices exist is unsatisfactory. Our working definition therefore consists of three tiers starting with a conceptualisation of how individuals come to engage in practising solidarity. They stand in a hierarchy of institutionalisation, with the first tier at the interpersonal and most informal level, and the third tier at the most formal – legal – level.

5.2 Three tiers of solidarity

Tier 1 – interpersonal level

5.7 The first, 'lowest' tier applies to the level of individuals. At that level, **solidarity comprises manifestations of the willingness to carry costs to assist others with whom a person recognises sameness or similarity in at least one relevant respect**.

5.8 The recognition of similarity[50] with one other person (or more) in one relevant respect[51] can take many forms. It entails the awareness of being associated – by choice, by 'fate', or other circumstances, with others. It is, paraphrasing Jaeggi (2010: 293), an instance of seeing one's own potential or actual fate, or that of loved ones, in the fate of another.[52] For example, I recognise similarity with my fellow air traveller in that we both will miss our connection flight due to our delayed departure.[53] Or I recognise similarity with a colleague at work in that he is a survivor of colon cancer and my sister is one as well (thus we both have very close experience of this disease, even if in my case my experience with it is not embodied). What counts as similarity *in a relevant* respect is dependent on the context of the practice that I am engaged in: if I sit on a delayed airplane and worry about making it to a meeting on time, then *similarity in a relevant respect* to the person next to me could pertain to both of us going to the same meeting, both of us making it on time, or both of us missing the connection. The fact that my neighbour is, for example, diabetic is immaterial for my practising solidarity (or not) in this particular situation, even if I may share this and other characteristics with her as well.[54] As our case study on pandemics shows (see Chapter 7), the timescale in which we conceive of risks and goals is an important factor in determining whom we regard ourselves as connected with. Finally, it should be noted that sameness can be perceived as facing a shared threat.[55]

5.9 We have already stated that the recognition of sameness itself does not represent solidarity unless it is accompanied by *acts*, that is, outer manifestations of my willingness to carry costs to assist others. To remain with our example, the recognition that the woman in the plane seat next to me will also miss her connection flight does not represent solidarity on my part (this would be better described as sympathy or empathy). If, however, I offer that she can use my mobile phone to make arrangements upon arrival, then this is an instance of a solidaristic practice. The same applies if, upon the initiative of my colleague at work, I sign up for a charity run to raise

[50] We use the term 'similarity' to include 'sameness' in the course of this argument.

[51] See also Calhoun (2002: 160), who speaks of 'categorical identities' of people who feel similar to each other in a culturally relevant respect (see also Sternø 2005: 194). Slightly different is Feinberg's (1970: 234) notion of 'community of interest', which is closely related to people "sharing a common lot, the extent to which their goods and harms are necessarily collective and indivisible'. Regarding global solidarity based on conditions shared by all people across the globe – a 'postethnic perspective", see Hollinger (1995: 109).

[52] Evers and Klein (2010: 178) refer to the same phenomenon of recognition of sameness in a relevant respect in their section on 'reasons for solidarity'. They mention "a notion of reciprocity" as a reason for solidarity: "People are willing to pay contributions because of their own (potential) need of health services later in life."

[53] We owe this example to Professor Ruth Chadwick, whose helpful contributions to the discussions leading to this report we gratefully acknowledge.

[54] The reference to the context of a concrete practice – rather than to an abstract identity – can also solve the dilemma pointed out by Jaeggi (2010: 298): "being a black lesbian professor in the United States, for example, should one relate to the black community all over the world (the 'African diaspora'), to women as such (black and white, gay and straight), to homosexuals (including men), to the upper-middle class, or to the academic community? Each of these classifications characterises a possible source of identification, but none of them actually compels someone to actually act on it."

[55] We thank Dr Kathryn Ehrich for mentioning this to us.

money for cancer research, donate money or volunteer significant amounts of time for this cause.[56]

5.10 Solidarity will regularly be enacted especially – but not exclusively – with the most vulnerable in a group. Vulnerability as such can be a factor giving rise to the recognition of sameness: in the acute vulnerability and need of my fellow human being I recognise myself when I have been, or will be, in such acute need.[57] Again, the practical context (time, place, social and economic factors, etc.) plays an important role because there are some vulnerabilities that I will never recognise as potentially my own (e.g. the possible vulnerability to be addicted to gambling if I never liked gambling, and neither do I lean towards any other addictive behaviours). It depends therefore on the particular person and the concrete practical context whose vulnerabilities would make me recognise similarity. Here, practices of solidarity regularly shade into practices of charity and altruism. Yet an important difference between solidarity and charity (see previous chapter on related terms) remains that solidarity is practised in a context of **potential or actual symmetry** within the group in at least one relevant respect ('we are all in the same boat' in this respect, even if we may be very different in many other respects in life). Another important difference in the point of gravity between solidarity and altruism is that altruism is more generally an attitude towards (all) others, whereas solidarity comprises concrete practices within a community of people who are sharing certain things in common (see previous chapter).

5.11 In most cases, it will be obvious what counts as similarity in the relevant sense, but sometimes this will be difficult to determine. As stated above, this chapter is not supposed to provide a static, fixed definition. Instead, the definition might sometimes require a degree of interpretation, and there might be cases when interpretations differ. This might lead to conflicting opinions on whether it applies in a given practical context. Such situations will require further debate and refinement of degrees of similarity. We do not consider this to be problematic. We hope that the explanations in the following sections will elucidate the type of sameness we envisage and that the case studies provide helpful examples of applying the definition. Where this is not the case, we call on others to advance the discussion.

Tier 2 – group practices

5.12 In cases in which a particular solidaristic practice at the inter-personal level becomes so normal that it becomes more widely seen as 'good conduct' in a given situation, it can solidify[58] into forms of institutionalisation. This is the case, for example, with self-help groups that practise more institutionalised solidarity. On this tier, solidarity can be described as **manifestations of a collective commitment to carry costs to assist others (who are all linked by means of a shared situation or cause)**. This is the second and arguably most prominent tier of solidarity. People who share a situation typically share certain risks or positive goals which emerge out of, or define, that situation. People negotiate ways of conduct in that situation (e.g. how to reduce the risk,[59] to prevent harm, or to reach a certain common positive goal). For instance, those with a particular disease might support each other, share health information to mimimise the negative effects of the disease, and organise events to raise funds for research into the

[56] In order to be in solidarity with people with colon cancer (and thus be willing to carry costs for their benefit), I do not need to be physically afflicted with colon cancer myself. It is sufficient for me to know people who have suffered from colon cancer and to have empathised with them to the extent that the situation of colon cancer has obtained personal meaning for me. Our working definition says nothing, however, about how and why such meanings come about; and why one person with a friend with colon cancer may associate herself with the cause of cancer prevention and another may not. That people are different in their emotional, social and political associations is hardly surprising. We are all embedded in complex nets of relationships to social, natural, and artifactual environments (Cook 2005, 2008).

[57] Societies and ideologies where individuals tend to be blamed for their own vulnerabilities (e.g. because they have not insured themselves individually against this scenario) are less conducive to solidaristic practices than societies where vulnerabilities are seen as an inherent part of human and social life against which societies best protect themselves collectively.

[58] As Jaeggi (2010: 288) reminds us, etymologically, the Latin term *solidus* signifies solidity, tightness, density, wholeness or unity, which are all forms of connectedness.

[59] See Weale (2002).

disease. The results of all these activities are common practices from which values or principles emerge that are shared by the members of such groups and communities.[60]

Tier 3 – contractual and legal manifestations

5.13 If these values or principles solidify not only into social norms but manifest themselves in **contractual or other legal norms**,[61] then we have an instance of Tier 3 solidarity, the 'hardest', most fixed, form of solidarity. Examples are welfare state and social welfare arrangements, but also contracts between different private actors and international declarations or treaties.

5.14 While the lower tiers of solidarity can exist without the higher levels, higher levels do not exist without having been preceded by lower levels. In other words, instances of Tier 3 solidarity have, some time in history, emerged out of Tiers 1 and 2, although the lower tiers might have changed following the institutionalisation into level 3. For example, it could be that Tier 3 is more or less intact, while Tiers 1 and 2 have (at least partly) broken away. Some claim this is the case with welfare state arrangements at present (e.g. ter Meulen et al. 2010). The reverse, however, does not apply: Not every practice of solidarity at Tiers 1 or 2 solidifies into tier 'higher' tiers, nor is it desirable that all of them do. There are certain things that smaller communities can do better than, for example, nation states, as the former are much 'closer to the ground'. Communities can react faster and often more effectively to changes or resistances in local and regional configurations of social, material, or political and economic factors.

5.3 Qualifications and explanations

5.15 Some qualifications apply to solidarity at all levels. First, as mentioned earlier, that solidaristic acts are preceded by the recognition of sameness with another person or group in one relevant respect means that the recognition of sameness is based on an overall symmetrical relationship,[62] not on an overall asymmetrical relationship (such as charitable giving, see Chapter 4). Secondly, it is crucial to again emphasise that solidarity manifests itself not in the sentiment of *empathy*: empathy, or similar sentiments, can of course be involved in solidaristic practices; however, solidarity, according to the definition above, takes the form of *enactments* of the willingness to carry costs to assist others. In this sense, solidarity is embodied and enacted rather than merely 'felt'.[63] Third, the extent of the costs carried is not decisive. Solidarity by our definition includes both enactments of the willingness to assist others which would incur relatively small costs – such as my offering my mobile phone to my fellow air traveler – and those which would incur significant costs, such as donating an organ. Fourth, solidarity is not beneficial for society *by definition*: while practices of solidarity in the context of health and bioethics regularly bring about solutions that are considered beneficial for individuals and/or for

[60] The notion of practice is one of the key elements in this definition. Knowledge, values and norms emerge out of individuals' experience in navigating their external environment in emergent time. Put differently, they grasp their environment in acting upon it. In this way, actors engage in 'actionable understanding' against a more or less stable, but largely tacit background of 'ongoing business' (Cook and Wagenaar, in press; Wagenaar and Cook, 2011; Campbell 1995). Solidarity is above all enacted, as we will explain later. It is this dimension of enacting which binds the different 'components' of the concept of solidarity, such as values, sentiments, activities, legal and contractual arrangements, and institutions together into one meaningful, recognisable and workable whole that is part of a larger societal context.

[61] Jaeggi (2010: 305) speaks of "crystallised" forms of solidarity. Arts and Verburg (2010: 25) describe European welfare states explicitly as "systems of organised solidarity".

[62] The emphasis on symmetry in relationships does not imply that the relationship between two people is necessarily symmetrical in every respect; it means only that the recognition of similarity or sameness in one relevant respect (that Mary and I are the same in the sense that we suffer from the same metabolic disorder; or that the man attacked by a group of drunk people is the same as me in the sense that I recognise human fragility). What is considered a relevant respect always depends on the particular context of the situation.

[63] Jodi Dean suggests that feminist writings on the topic of solidarity are a rare source of explicit discussions of the embodied dimension(s) of solidarity (even if they do not take place under the label of embodiment). As Dean (1996: 20) argues, it is exactly these sensory, sensual, or emotional properties (Dean does not use the term embodiment in this context either) that points towards a dilemma inherent in the notion of solidarity. If family relations, for example, are taken as templates of an ethic that can be extended further, then this works only in theory, as solidarity is a *feeling* that cannot be discussed in an abstract manner. Thus, so Dean concludes, solidarity cannot be extended beyond the conditions under which it is expressed.

public health goals, not all solidaristic practices are considered beneficial by everyone, or even by most of us. For example, if I recognise similarity with a belligerent separatist group and join their military cause by enlisting in their army, this could be seen as a manifestation of my willingness to carry costs to assist others and thus constitute a solidaristic practice. Yet most people would not see this as a beneficial practice of solidarity. In addition, institutionalised practices of solidarity always exclude certain people. For example, welfare state programmes are typically difficult to access for immigrants.[64] Fifth and finally, solidarity does not exclude acts of giving on the basis of contractual relationships in principle. Diagnosing that certain actions are based on contractual or legal obligations does not mean that they cannot, at the same time, be enactments of solidarity. This is regularly the case within tier 3 solidarity).

Related concepts

5.16 In the previous chapter, we have pointed out where the differences in the points of gravity lie between solidarity and other concepts such as altruism, charity, dignity etc. Unlike these, empathy[65] and friendship are not frequently discussed as concepts related to solidarity in the literature; however a brief discussion of similarities and differences to our understanding of solidarity seems relevant in the given context.

5.17 The difference between solidarity, in this working definition, and empathy, is that empathy can consist of a mere inner sentiment (I walk by an injured person in the street, imagine myself in her situation and feel for her), while solidarity requires some level of outer articulation (e. g. I offer the person help). Another difference is that while empathy *requires* such a sentiment, solidarity *can* entail such a sentiment as preceding an act of giving, but does not have to; an act of giving out of solidarity can be based on a purely rational, or even habitual, decision to do so.

5.18 The difference between solidarity and friendship exists both in degree and in kind. While both entail the recognition of similarity in relevant respects, the biographies and life-worlds of friends are so closely intertwined that their 'similarities' – in the sense that they share the same situations – are typically plenty. The difference to solidarity is mostly one of degree, as friendships also typically involve manifestations of the willingness to assist each other and I may be even more willing to accept costs to assist a friend than I am willing to accept costs to assist a person with whom I share only relevant thing in common. However, there is also a difference in kind: While for us to speak of solidarity, some minimal outer expression of the willingness to accept costs to provide assistance must be present, this is not a requirement for friendship. Friendship is constituted by many other practices for which terms such as affection, loyalty, and continuing attention would fit better than mutual assistance (although the latter is often involved in friendships as well). Friendship is typically *deeper and broader* than solidarity, and it is primarily bilateral: the cohesion in a group of friends derives primarily from the dyadic bonds rather than from a collective substrate. In other words, unlike solidarity, friendship does not have any second and third tier. (The same applies, *a minore ad maius*, to love, loyalty within a family etc.). Moreover, friends know each other in person, which is not a requirement for solidarity.

5.4 The working definition in context: do solidarity and autonomy conflict?

5.19 In recent years, many authors have criticised the strong focus on autonomy in bioethics (e.g. Sherwin 2011; Widdows 2011; Fox & Swazey 2008; see also section on public health ethics in Chapter 3). This raises the question whether solidarity and autonomy are conflicting concepts. We argue that the extent to which they are complementary or competing depends on the way in which individuals and personhood are conceived. For example, if we follow a liberal tradition and consider the autonomous individual[66] as the central unit of analysis whose rights must be

[65] Sympathy will not be discussed here as it is more pertinent to asymmetrical interactions which characterise charitable acts, for example.

[66] Although autonomy plays an important role in individualism, the two are of course not synonymous. Baarts (2009) offers a review of the literature portraying individualism and collectivism as co-existing, or mutually exclusive, from the perspective of

protected and whose interests the person should be able to follow, this autonomous individual could still feel, and act upon, solidarity with other groups or people. In this model, in order to obtain solidarity within a particular collective, one would need to either: (a) chose a collective where the desire for mutual assistance (solidarity) is inscribed in the relationships anyhow[67] (e.g. in many nuclear families), or (b) convince individuals that there is a good reason to act in solidarity with others. In this way, the goal of solidarity is entirely compatible with a focus on individual choice and autonomy and on liberal rights as overarching values.

5.20 The second model is different from the liberal model in the way in which it conceives of individuals. Individuals are not seen as given and clearly bounded entities, but as people whose identities, interests, and preferences emerge out of relations to others. For example, being born into a family, choosing and spending time with friends, and living in a certain community are all events and characteristics which shape who people are. Thus, relations to others, in this model, are not seen as independent from, but as part of, the person. Consequently, solidarity can be seen as something that is an 'innate' need (and characteristic) of people. While we are all the same in the sense that we all are solidary with others, we are different with respect to whom we feel solidarity with, and with regards to why, and how, we act upon it. This has two consequences. First, as in the liberal model, solidarity within a collective can be achieved either by focussing on entities where mutual assistance is inscribed in the relationships between people (e. g. within families, small villages, sometimes colleagues at work, or in associations), or people can be convinced that there is a good reason to feel sameness with a particular group and act solidary. Second, and in contrast to the liberal model, because the individual is seen as emerging from the relations in which she is embedded, solidarity is at least of equal importance to individual rights and interests. None of the two, communal or individual interest, *a priori* weighs more heavily or overrules the other.

5.21 The main difference between the two models is that in the liberal conception, solidarity can never be claimed by state actors or anyone else; it is always already present, or it needs to be argued (in the sense that people need to be convinced). In the second model, which we term the relational model,[68] solidarity is seen as a pre-condition for personhood, interests, and rights. Here, solidarity precedes – not as a normative goal but as the diagnosis of a fact – the protection of rights and the articulation of interests.

5.22 In this way it is also possible to solve instances such as the "ideological paradox" that ten Have & Keasberry talk about in the Dutch context (1992: 465), namely that "[the Dutch] welfare state incorporates an ideological paradox exposing itself in a tension between a collectivist ideology and an ideology of self-help and individualism". If solidarity precedes individualism, then the objective of seeking self-help, which poses – as ten Have and Keasberrry argue – a positive moral duty on the person, can be seen as the manifestation of a duty towards the collective that one is an inseparable part of – namely to avoid costs for the collective as much as possible.[69]

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construction work safety. Very helpful is also Wilson's (2007: 353) distinction between three concepts of autonomy, where the first "refers to the *capacity* to make autonomous choices', the second refers to the autonomous choices *per se* (on the basis that autonomous choices are worthy of respect), and the third refers to 'a sphere of decisional privacy".

67 We would be hard stretched to argue that such fundamental bonds between humans are 'chosen'. As argued in the *Stanford Encyclopedia of Philosophy* (2001): "I didn't choose to love my mother and father, to care about the neighbourhood in which I grew up, to have special feelings for the people of my country, and it is difficult to understand why anyone would think I have chosen these attachments, or that I ought to have done so."

68 'Relational' in the sense that Baylis et al. (2008) use it; communitarian, and personalist approaches (see Chapter 2) can be subsumed under our use of this term.

69 Ten Have and Keasberry (1992: 474) highlight the objective to avoid costs for the collective in their recommendations for a redesign of the Dutch welfare state: "[T]he function of government in the welfare state should be reconsidered. Instead of direct regulation and detailed control, more freedom should be granted to private initiative and personal responsibilities. The role of government should be reduced to erecting a structural and procedural framework within which health care would have to be provided both on a basis of social security legislation and on a basis of private initiative." Regarding the role of solidarity in this specifically, they argue that (1992: 475): "On the other hand, health care policy today is in many ways involved in attempts to shift the burden of care from the state to the individual. In doing so, a new type of solidarity might be

5.23 Thus, although our definition has been informed by relational positions (which see people's identities and preferences as co-determined by the relationships that they are embedded in), they are not incompatible *in principle* with liberal conceptualisations of society. According to our definition of solidarity, practices based on solidarity could be conceptualised both as the result of a deliberate decision of an autonomous individual (whose autonomous existence precedes her social relations), or as something that co-emerges with the dense web of our social relations which literally "make up people" (Hacking 2006). In other words, our definition of solidarity could be embedded in a concept of a society where solidarity is seen as something that people decide to act upon (or not). Alternatively it could be embedded in an understanding of a society where solidarity is an inherent aspect of humanness and personhood. Our understanding could be seen as the best common denominator of the approaches discussed.

5.24 Our understanding of solidarity bridges the separation between prescriptive and descriptive uses of the term. The working definition, as discussed so far, is descriptive as it helps to determine whether solidarity, or other terms, best describe a certain form or context of social/political interaction. It is, however, prescriptive insofar as it contains substantial statements about how to understand the person; namely, as at least partly shaped by her social relations, including those that pertain to her in her capacity as a citizen. What follows from this is that **societal and political arrangements that consider these social relations are typically preferable to arrangements that do not**.

5.25 In the following chapters, we apply the working definition to three case studies – biobanks, pandemics, and lifestyle-related diseases. In order to do so, we introduce some basic information on the debates in these fields. We then showcase some of the consequences our understanding of solidarity would have in the real world of policy making and governance. These exemplify how a focus on solidarity might help to re-calibrate existing discussions, shift entrenched debates, and set new agendas for policy making. Due to the nature of this project, our suggestions are merely offered as examples. We hope they can stimulate debate and inspire others to also continue work on this topic.

promoted: solidarity not in the sense of an endorsement of redistributions of income, but in the sense of a disposition to accept responsibility for one's own life and one's own choices in life. In its latter sense solidarity may become a reason for self-exclusion from care as well as a reason from private initiative in organizing and financing self-care in new social support systems." This use of the term solidarity may come very close to what Scholz (2008: 46) calls "parasitical solidarity". Moreover, this approach of ten Have and Keasberry is ill-equipped to solve problems such as free-riders as it relies on the willingness of the individual to contribute to cost-containment as far as possible, and to employ the principle of subsidiarity in her own life: She will only seek help from the community insofar as she cannot help herself (see also Ter Meulen et al. [2010: 6], who argue that individualism is also a positive value to the extent that it fosters individual responsibility).

Chapter 6

Solidarity in practice I: research biobanks

Chapter 6 – Solidarity in practice I: research biobanks

6.1 Research biobanks: background

6.1 In the following chapter, we briefly summarise the current debate surrounding research biobanks and the main areas that are contested amongst scientists, ethicists and policy makers. We then go on to apply our working definition of solidarity to these areas, trying to show what difference it might make to discuss the issues through the prism of solidarity as laid out in the previous chapter. Finally, we make a few suggestions for policy changes which would be useful if solidarity were to be adopted as a guiding principle.

6.2 Practices of solidarity can be particularly helpful in addressing current challenges in the field of research biobanking. Such biobanks raise the question of solidarity at several levels. On the one hand, collective benefits are the watermark of the very concept of research biobanking. Setting up a research biobank is typically a long-term project demanding considerable investments – financial and otherwise – without showing any results or having any immediate impact for a while. Only altruistic values and those prioritising collective benefit over individual interest can therefore be used to justify individual investments (data and biological sample donations) in research biobanking, as research participants are typically not paid. On the other hand, research biobanking is embedded into a rhetoric of personalised medicine, suggesting individual benefit. This renders research biobanks an embodiment of a promise that they might struggle to fulfil.

6.3 Research Biobanks have received a lot of attention in the last two decades. It was in particular the Icelandic *Health Sector Database* project, which sought to bring together health records, genealogical records and DNA samples of the entire Icelandic population (Pálsson & Rabinow 2001; Greenhough 2007) that drew attention to a phenomenon that is indeed much older. The systematic collection of biological samples together with disease and/or other phenotypic information is almost as old as clinical medicine. What made biobanks a greater topic for discussion since the beginning of the new century are: (1) the large scale of collections; (2) the systematic approach to sample and data collection and data generation; and (3) the possibility of automatisation of data collection and comparison, the purpose of which is not clinical diagnosis but research. While traditional small-scale collections (e. g. of tumour tissue in pathology departments of hospitals) continue to exist, recent types of biobanks contain samples and data from hundreds of thousands of participants, and therefore exciting new opportunities for data linkage and data-mining. This latter kind of 'new' biobanks (Corrigan & Tutton 2004; Gottweis & Petersen 2008), and networks of biobanks, where large amounts of samples and datasets can be mined to discover new patterns (e.g. genetic markers that correlate with a particular disease phenotype), have been seen to pose particular ethical and legal challenges. Most prominent in this context have been concerns in four domains: data protection, confidentiality and privacy; genetic discrimination; ownership and informed consent; and return on investment (including access to findings).[70]

[70] See also the NCoB background paper on genomics, health records, database linkage and privacy,which addresses the same issues in a slightly different configuration (http://www.nuffieldbioethics.org/sites/default/files/files/Genomics_health_records_database_linkage_and_privacy_background_paper.pdf).

6.2 Data protection, confidentiality, and privacy

6.4 Traditional sample[71] and data collections, which often contained personal information such as names and dates of birth of the sample originators, were typically not digitalised, and thus not accessible from outside the institution; this situation has presented a factual obstacle to privacy violations. In contrast, current large-scale biobanks make it *technically* possible for a relatively wide scope of people to access clinical, personal and other data stored in databases (e.g. life style information, medical histories etc.). This situation has rendered data protection, confidentiality, and privacy a key concern in the context of biobanking in the 21st century (Lunshof et al. 2008).

6.5 The definition of privacy is far from being clear-cut. In general, privacy signifies a negative freedom, namely the freedom from interference with, and intrusion into, one's personal realm by third parties. Privacy is never an absolute right: in every jurisdiction in the world, legal provisions limit the right to privacy for the sake of other goods (e.g. search warrants for the good of prosecuting breaches of the law; duties to disclose income for the sake of taxation; duty to disclose infection of certain contagious diseases for the sake of preventing further spread).

6.6 Confidentiality is different from privacy in that it pertains to prescribing a limited use of data and information once it has been legally obtained. For example, while the unauthorised access to my credit card details constitutes a breach of my privacy, the sharing of my contact details with marketing agencies by my credit card company without my explicit consent represents a breach of common confidentiality standards. In the realm of medical research, where identifying details could be inferred from data or information that do not *per se* disclose personal identities (Homer et al. 2008; Lowrance & Collins 2007, Lin et al. 2004), privacy and confidentiality regularly overlap.

6.7 In the context of biobanking specifically, as Kaye et al. (2009: 23) point out, "[o]nce data are anonymised, it is very difficult to show a breach of privacy as a matter of law". Regulations in many countries have therefore assumed the (re-)identification, or the attribute disclosure,[72] of individuals whose samples and data are stored in a biobank as actual or potential infringements of privacy (see e.g. Lunshof et al. 2008). Especially in light of the possibility of discrimination – e.g. in insurance or employment contexts – this assumption has been very useful so far. Against the backdrop of increasing numbers of countries implementing non-discrimination legislation, and in the context of large-scale biobanks, where research findings are often meaningful only at the aggregate and not at the individual level, a reassessment of the meanings of privacy seems timely (e.g. Taylor 2008; Lunshof et al. 2008; Wijst 2010). Such an endeavour would need to be sensitive to the different stakes inherent in different research, institutional and national contexts.[73]

6.8 Privacy and confidentiality are not to be seen as claims by people who have 'something to hide', but instead as the rightful privilege of participants to decide what information they want to share with whom and in what contexts. Consequently, assessments of privacy and confidentiality infringements need to consider this; answers to these questions will necessarily depend on the

[71] Samples – which are sometimes referred to as biospecimens – include all kinds of biological material such as blood, extracted DNA and cell lines. The latter seems to be particularly challenging in the context of privacy. The proliferation of 'immortalised' cell lines cannot be controlled by any reliable method (Skoot 2010). We are grateful to Dr Jeantine Lunshof for very helpful discussions on this aspect.

[72] Attribute disclosure is different from (re-)identification as it does not pertain to the disclosure of a particular identity *within* a biobank, but disclosure that a particular person participates *in* a biobank: for example, the mere fact that a person is in a biobank which comprises only samples and data from people with a particular trait or condition could be seen as infringing the person's privacy (see Heeney et al. 2010).

[73] Very useful in this context is Heeney et al.'s (2010) notion of the 'data environment'. This will regularly be configured differently in contexts of publicly funded research biobanking than in commercial research biobanking.

concrete context of (voluntary or potentially involuntary) sharing of data and information. In addition, these answers will depend on individual values and preferences.[74]

6.3 Discrimination

6.9 The issue of discrimination is closely related to data protection, confidentiality and privacy: breaches of data protection standards and privacy rights can have consequences that give rise to discriminatory practices. Discrimination can be measured in subjective and objective terms. The former would accept whatever scenario an affected individual would perceive as discriminatory for this person. The point of reference for the latter would be to set standards that apply to everyone (e.g. in a law, in a governance framework etc. Non-discrimination laws are typical examples of using objective standards of discrimination).

6.10 While the issue of genetic discrimination has received ample attention in the context of biobanking so far (e.g. van Hoyweghen et al. 2010; Greely 2005), this is not the only type of discrimination that could result from biobanking. For example, if I am suffering from an autoimmune condition and have donated DNA and data to a disease-specific research biobank, then I may be worried about possible discrimination if my employer learned of this fact. Moreover, discrimination does not necessarily manifest itself in the realms of insurance and employment alone. Heeney et al. (2010) have highlighted other discriminatory practices such as 'redlining', which entails the exclusion of certain groups of individuals from services and goods on the basis of a characteristic that they share.[75] This practice is particularly difficult to pin down as its borders with legitimate marketing practices, such as target advertisement to certain groups, are fluid. The risk for redlining (or reverse redlining; see e.g. Bavafa 2010) emerges where data are mined and when interfaces with users (insurers, landlords, employers, retail companies etc.) exist which are not bound by explicit non-discrimination provisions. Finally, discrimination need not be based on characteristics that are explicitly recorded in the biobank, but also on those that can be inferred from it (for example, if it is known that I have an autoimmune condition it can be inferred that the amount of sick leave that I will take is likely to be higher than in the average population) (see Tavani 1999a, b; Tavani 2004).

6.4 Ownership and informed consent

6.11 Questions about ownership of the samples and data in biobanks are both complex and controversial (e.g. Dressler 2007; Charo 2006). Not only do regulations and rules relating to ownership questions vary from one institutional and national setting to another, but they are also configured differently with respect to samples, data and information.[76]

6.12 Many research biobanks bypass the controversial issue of ownership by including a waiver to claiming ownership rights in their informed consent forms. Other biobanks – especially those that receive public funding – operate with models that are more nuanced. For example, the

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[74] In the field of large-scale biobanking in genomics research in particular, some initiatives have started to challenge the utility of privacy in genomics in general. Noteworthy examples in this context are the *Personal Genome Project* in Harvard, which involves the publication of DNA sequences data, clinical, and personal information on the Internet (http://www.personalgenomes.org/; see also Angrist 2009, 2010), and the *Genomes Unzipped* initiative, where the publication of genetic information of a group of scientists is embedded in a critical reflection of ethical, societal, and regulatory dimensions (http://www.genomesunzipped.org/). Other initiatives, rather than reassessing the notion and utility of privacy altogether, have suggested new solutions such as the introduction of a 'Bio-Pin', which would replace the recording of personal data altogether (Nietfeld et al. 2011).

[75] For example, individuals with a particularly good health status could be singled out to be offered certain insurance policies. See also Heimer 2003.

[76] The term 'samples' is seen here as referring to the biological material stored in biobanks – such as tumour tissue, bone specimens, or DNA obtained from blood. 'Data' pertains to the (often quantified, but sometimes narrative) representations of (a) samples stored in a biobank, and (b) the originators of the samples. Examples include (a) the numbers of single nucleotide polymorphisms (SNP) contained in a DNA sample, or the narrative description of a tumour sample, and (b) personal data such as a participant's name, birth year or weight. 'Information' signifies the surplus that data yields when it is has been rendered meaningful in a specific context: for example, when a DNA sample in a biobank contains a genetic marker (datum) which is known to correlate with a disease, then it turns into information. Also details about a person's medical history are often information (see Pálsson & Prainsack 2011).

participant can remain the formal owner of the samples and data obtained, but cannot claim property rights. Other institutions, such as UK Biobank, claim ownership rights of the samples and data in the biobank for the explicit purpose of enabling communal benefits; they refrain from certain rights that traditionally come along with ownership, such as selling samples. For this reason, the terms 'stewardship' or 'partnership' are preferred over 'ownership' by such biobanks in this context (see also Winickoff 2007; Tutton & Prainsack 2011). These approaches typically manifest themselves in trustee or stewardship arrangements (see, for example, O'Brien 2009; Winickoff & Neumann 2005), where an independent intermediary is entrusted with protecting the interests of participants; the trusted intermediary oversees access, negotiates privacy and confidentiality protection standards etc. Such intermediaries could also set priorities for access to data and biomaterials.

6.13 The issue of informed consent is central in this context. Not only in arrangements where participants retain ownership, but also within trustee, stewardship and similar models, it has been argued that participants need to be informed of any intended research that the samples, data and information will be used for. Under this model, if the research question changes in the course of the lifetime of the biobank, then the information cannot be used unless participants have been re-contacted and given their informed consent for the new question too. Especially in the context of large-scale and hypothesis-free data mining, however, this ideal idea of informed consent has encountered problems of both a conceptual and practical nature. Conceptually, it has been argued that it is often unclear at the time of collecting samples and data from participants what insights the initial data-mining will yield; thus it is very difficult, if not impossible, to formulate a research question for participants to consent to, or even name the diseases and conditions in the context of which the samples and data will be used in the future. Practically, because results from many large-scale genetic and genomic research studies are often pertinent primarily at the aggregate level, questions have been raised as to the suitability of informed consent procedures focusing on individuals rather than groups (Chadwick & Berg 2001).[77] Finally, Lunshof et al. (2008: 4) argue that if informed consent is conditioned "on the assurance or even the unchallenged expectation of full genetic secrecy", such informed consent may be invalid in the context of large-scale genomics research, due to the impossibility of guaranteeing such secrecy (Homer et al. 2008; Greely 2007; on the right not to know, see e.g. Hallowell 1999; Andorno 2004).

6.14 Against this backdrop, scholars have called for a reassessment of the concept of informed consent. Such suggestions include the changing of informed consent from it being a one-off event to an ongoing dynamic process (McGuire & Beskow 2010; Kaye et al. 2009; Caulfield et al. 2008), or to replace the objective[78] to inform participants of all possible uses for their samples and data with the commitment to veracity.[79] Veracity refers to the commitment to telling (potential) participants as much as one knows, but also to admitting that it is impossible to know everything (Lunshof et al. 2008; Church et al. 2007). Veracity is considered by these authors as the core value underlying blanket or open consent models, which entail that participants are

[77] See Kaye et al. 2009. Attempts to operationalise group consent into large-scale genetics and genomics research have so far suffered from problems of determining the scope of the relevant group, as well as the criteria to delineate it. See, for example, Reardon 2005 and Hoeyer 2008.

[78] Whether or not this is a legal requirement varies from one jurisdiction to another. In the UK, it is unclear whether this is a legal requirement. As Kaye et al. (2009: 6) point out, "[u]nder the Data Protection Act 1998, 'explicit consent' is the standard for consent to the processing of sensitive data such as health data. The Act does not stipulate, however, what 'explicit consent' is, nor what the content of explicit consent should be." The authors refer to Directive 95/46/EC, which the UK Data Protection Act is seen to implement, which defines consent as "any freely given specific and informed indication of his wishes by which the data subject signifies his agreement to personal data relating to him being processed" (Kaye et al. 2009: 6).

[79] Church et al. (2007: 9) argue that "the open informed consent protocol […] represents a sincere commitment to veracity. It is our belief that veracity is fundamental to the solicitation of informed consent from prospective research subjects, and we treat veracity as an ethical obligation closely connected to the basic human research principles of respect for autonomy and beneficence. Moreover, veracity is a crucial element in establishing and preserving the public trustworthiness of the scientific research community." The latter aspect – preserving (and arguably also reinforcing) the trustworthiness of the scientific research community is particularly pertinent to the spirit of the partnership model put forward in this report (see also Lipworth et al. 2011).

requested to consent 'in bulk' to any research that may be carried out with their samples and data. Research ethics committees, and/or biobank governance boards, would then approve requests for concrete instances of additional research (see Hansson et al. 2006; Kaye et al. 2009). This approach, however, has been criticised because of the impossibility of giving informed consent if participants do not know what it is that they are consenting to (Caulfield & Kaye 2009; e.g. Bhan 2010).

6.5 Return on investment for participants

6.15 'Return on investment', here, is to be understood broadly, including not only financial returns (from patents etc.) but any kind of benefit that could result from the participation in biobank-based research for participants. Examples of benefits range from tangible financial benefits, such as revenues from intellectual property rights (for example, from patents on diagnostic procedures or devices developed on the basis of the data and samples in the biobank;),[80] to clinically useful information for the individual, to more general benefits such as advancing knowledge about a particular disease aetiology.

6.16 With regards to large-scale research in genetics and genomics specifically, many discussions have focussed on what kinds of information should be fed back to individuals. In contrast to the results of the analysis of a tumour specimen in the context of an individual treatment decision, or the analysis of a DNA sample in the context of genetic counselling, the results of the analysis in large-scale genetics and genomics research often have clinically relevant meaning, primarily in aggregate form. Illustrative examples of the latter are so-called genome-wide association studies (GWAS). These entail the comparison of loci across the entire genome between a group of people who do share a particular characteristic (e.g. a Parkinson's diagnosis) and a 'control-group' of people who do not have the characteristic. If it turns out that within the group of people who suffer from Parkinson's disease, there is a significantly higher prevalence of a particular genetic variant, then this could indicate that there is an association between that particular locus and the disease (although the association does not say anything about *causation*, which would need to be explored in separate studies). As neither the function of the genetic marker, nor the strength and direction of its effect, have been established, the clinical utility of this information for individuals who carry the marker is unclear.[81] It has been argued that in such cases, this information should not be fed back to participants, not only due to considerations of logistics and cost, but also of the wellbeing of the participant (who could be needlessly upset) (see also Shalowitz & Miller 2008; Miller et al. 2008; Boenink 2008). Similar discussions have emerged around the question of whether or not to inform participants of incidental findings, that is, discoveries that were made as a by-product of biobank-based research (for example, in the process of a large sequencing study it turns out that a particular participant carries a deletion in a gene which is known to be associated with a particular disease). Ravitsky and Wilfond (2006) propose that assessments of the analytic validity and the clinical utility of specific results should be the basis upon which decisions about communicating results to participants should be made. Noteworthy in this context are also initiatives such as the UK10k project.[82] This is a Wellcome Trust funded endeavour to study detailed DNA sequences of 4,000 healthy participants in existing research cohorts, and to contrast them with the DNA of 6,000 people with extreme and rare health problems to obtain a better understanding of genetic and environmental factors influencing both common and rare disease. Researchers in this project have developed a nuanced protocol outlining the circumstances under which particular kinds of incidental findings will be fed back to participants. In the context of the UK10k project specifically, incidental findings will almost never be fed back to participants in the healthy population groups, and only in a very narrowly defined range of cases in the special disease groups.

[80] Informed consent forms for participation in biobanks routinely contain waivers of claims to intellectual property rights.
[81] This is not to say, however, that this information has no utility at all; it can have considerable personal or social utility (see also Cherkas et al. 2010).
[82] See http://www.uk10k.org/ (accessed 14 July 2011).

6.6 Current challenges

6.17 There are currently a number of unresolved issues in the field of research biobanking. Issues around ownership have been addressed but not solved; data protection and privacy are still contested, with some scholars arguing that the concepts of privacy and confidentiality sit uneasily with contemporary large-scale biobanking; and, as mentioned above, traditional ideas and practices of informed consent are increasingly being challenged (e. g. Allen & McNamara 2011). In addition, the heavy administrative, logistical and financial costs incurred by current (re-)consenting and re-contacting requirements for biobank-based research – which also manifest themselves in requirements for research ethics approval – have been criticised as unduly impeding disease research. Taylor (2008: 32), for example, argues that "[l]inked data are crucial for research and improving health-care quality. People might fear that information will be revealed or misused, but the impulse to block all access in the absence of consent is mistaken." Moreover, as Lunshof (2006) argues, the impractical requirements for ethics approval for clinical trials were blamed for the scarcity of data from randomised clinical trials during the SARS outbreak (see also Glaziou & Chalmers 2004). Lunshof (2006) summarises that

> "First, the traditional content of medical ethics and its guiding principles might not be sufficiently applicable anymore to the questions that are raised by current research, especially in genomics. The 'protection model', which is intended to safeguard individual rights and interests and features 'autonomy' as the core concept, is not equipped for the assessment of genetic population studies with its focus on groups and communities, and using data and samples that have different levels of identifiability. Also, the data that are collected in pharmacogenetic studies have an information content that is different from that of genetic data that are collected in research on rare hereditary disorders. The possible effect on study participants is not comparable. Therefore, rights and interests must be redefined accordingly. The same holds for the ethical principles that are to be applied. First attempts to develop new normative frameworks have been made. Notably, the set of principles as proposed by Knoppers and Chadwick [2005]http://www.nature.com/nrg/journal/v7/n3/full/nrg1810.html - B2 that includes reciprocity, solidarity and citizenry could offer guidance in the ethics review of population-based genetics research."

It is exactly in this light that the following section will formulate a number of approaches to tackle some of the current issues in relation to participation in biobanking.

6.7 Participation in research biobanking: a solidarity-based approach

6.18 We propose an approach to participation in research biobanking which is based on the definition set out in Chapter 5: solidarity as shared practices reflecting a collective commitment to carry 'costs' (financial, social, emotional or otherwise) to assist others. Our approach is based on the core assumption that when individuals decide to participate in biobank-based research, they are willing to accept the possibility that certain level of costs[83] may need to be carried by them for the sake of communal benefit.

6.19 We take this willingness to be mainly based on the recognition of relevant similarity (see Chapter 5) with other participants in the biobank and, to a lesser extent, with those who might in the future benefit from the results. Sameness in a relevant sense is obvious with regards to those engaging in the same practice – that is, participation in the biobank. Participants can expect to assist others, as results from the biobank might contribute to clinical developments that they themselves or fellow participants might benefit from (NB: this is not to be confused with an expectation of reciprocical benefits; the main point is the expectation to assist others). Similarity with future individuals could be based on the fact that these individuals might share certain characteristics or features (e.g. if the biobank is devoted to derive information about a particular illness). It could also be conceived in more general terms on sharing a context: for

[83] The term 'costs' here is again to be understood widely; it includes financial costs, emotional or psychological costs, mere inconvenience, and also actual harm.

example, when I decide to follow the request of UK Biobank to become a participant based on the recognition that my participation may help many others who – like me – need medical treatment from time to time.

6.20 Going beyond the empirical claim that most participants will be prepared to carry costs when joining up with a biobank, we suggest that future (publicly-funded) biobanks *should* be modeled on the basis of the solidarity assumption, based on and expecting this willingness from participants the outset. Of course, these costs must be very limited for this model to be acceptable. In many instances in research biobanking, the risk of harm is very small and can be minimised with good policy and governance structures and strategies. In addition, we present further arguments for this shift in the following sections and suggest a number of changes to governance structures for its implementation.

Central elements and arguments

6.21 Our approach entails several elements: (a) a new approach to agreement for research participation (participation agreement); (b) solidarity-informed perspectives on (re-)consenting and communicating findings to participants; and (c) a conceptual shift towards harm mitigation strategies. New research on existing samples and data in biobanks would be unaffected by this model, which would apply only to new participants signing up to a biobank. The use of existing samples and data in a biobank is governed by specific frameworks nationally and internationally.

The participation agreement: from specific consent to veracity

6.22 As Margit Sutrop (2011: 376) reminds us, "the principle of informed consent was introduced in medical ethics mainly to protect individuals against possible harm". This notion has arguably become overshadowed by narrow interpretations of individual autonomy, which interpret informed consent not only as one of its manifestations but as a quasi-synonym for autonomy itself (e. g. McGuire et al. 2008; O'Neill 2003; Wilson 2007). Also in light of increasingly litigious societies, informed consent has assumed a new role as a 'stamp of approval' for research participation that is seen as ethically unproblematic (for a discussion of this situation see Hoeyer 2008).[84] The result is, as has been pointed out above, a situation where significant resources are channelled into developing and implementing policies and protocols for (re-)consenting and re-contacting research participants. While this is mandated in scenarios where the risks for research participants are considerable (e.g. health risks), in connection with contemporary biobank-based research – especially in the field of genetics and genomics – risks for participants are currently regularly very small. In many instances of biobank-based research, the most significant risks for individuals are the possibility of involuntary and/or unauthorised identification, and possible scenarios of discrimination that may emerge from it. To the best of our knowledge, instances of actual discrimination based on a participant's involvement in a biobank (including large genetic research studies or cohorts) are extremely rare.[85] Moreover, recent research has increasingly drawn attention to the very limited predictive value[86] of – particularly current common-variant genetic – markers at the individual level, a phenomenon that insurance companies also seem to recognise (Nabholz & Overbeck 2004; Prainsack 2008).[87] In addition, countries such as the US have started to issue non-discrimination

[84] With regards to genomics research specifically, de Vries and Horstman (2008) argue that informed consent assumes the role of governing uncertainty.

[85] See, however, the conflict between the Havasupai Indians and Arizona State University; see Harmon 2010.

[86] DNA sequencing – that is, the mapping of all (protein producing) elements of DNA rather than focussing only on certain areas that are 'flagged up', which is commonly the case – could change the limited predictive value of most genetic markers. A more comprehensive approach to DNA mapping such as DNA sequencing could show the presence of rare variants in a given individual, and the effects of these could be much larger than those of common variants.

[87] The reason for insurers to have voluntarily agreed to adhere to a moratorium on the use of genetic information for insurance underwriting in most instances in the UK, for example, is that they currently do not consider themselves as being disadvantaged by adverse selection on the basis of genetic testing. Yet with the increasing uptake of (also direct-to-consumer [DTC] variants of) genetic testing, problems of adverse selection could arise (e.g. consumers of DTC genetic testing, for example, could 'over-insure'). Thus it can be expected that insurers will increasingly insist on 'symmetrical

legislation.[88] Thus, in many contexts of biobank-based research, the risks that participants face today are much smaller than risks encountered in other situations of disease research or clinical trials. This calls for a reassessment of costly (re-)consenting and formal ethics requirements, as it can be argued that these resources would be better invested in disease research itself.

6.23 In our model, a person's autonomy remains a guiding principle at the stage of informing individuals about possible risks and benefits of their participation in biobank-based research. It is, however, interpreted in such a way that it is acceptable for a person in her capacity as an autonomous actor to accept a certain level of risk and uncertainty (as we do in almost all realms of life). This entails that potential participants, at the stage of recruitment, are informed in detail about the mission of a particular biobank, its funding and governance structures, and what it hopes to achieve. As empirical research has shown that commercialisation of body substances and personal data is an important concern for potential research participants to consider (for an overview see Hoeyer 2008; Gere & Parry 2006; Parry 2004), such an initial disclosure should highlight current arrangements and policies of the biobank in this regard, and an assessment of how this could change in the future. Furthermore, while such an initial disclosure statement on the side of the biobank would regularly include disclosure of research questions and contexts that the biobank supports at the time of recruitment, it should also include a statement that the biobank – and thus the samples and data of the participant – may be used to serve research that cannot yet be envisaged, and that appropriate research ethics approval will be obtained wherever laws and regulations require this.

6.24 Such a disclosure statement of the biobank at the recruitment stage would also include a list of risks and benefits insofar as they can currently be foreseen, with an explicit note that this list may not be exhaustive. Potential research participants would then be asked to consider signing an 'agreement to participation' statement.[89] Especially in the rare situations where the potential risks for participants include scenarios for discrimination leading to financial and economic losses, such an agreement to participation may precede (or include) a personal risk self-assessment that the person will be asked to carry out (initiatives such as the Personal Genome Project at Harvard University currently have such systems in place).

6.25 If a person decides to agree to participation, she confirms that she has considered the possible advantages and disadvantages of such research participation, including worst-case scenarios pertaining to her own personal, familial and social context. Before and after signing the agreement, participants will be able to enter a dialogue with (and retain contact details of) a representative of the biobank who can be reached at any time, should further questions arise.

6.26 The participation agreement would amount to an enactment of solidarity as understood in this report: the potential disadvantages and the degree of uncertainty the participant is prepared to accept reflect her willingness to carry costs to assist others.

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information' (i. e. to have access to the same level and detail and information as their customers). We are grateful to Ine van Hoyweghen for helpful discussions on this point.

[88] Yet, as Gurwitz (2011) argues, research biobank participants "who are protected in their home country may still face discrimination by employers or insurers in another. Such concerns risk discouraging potential donors and will hinder international biobanking efforts." This situation needs to be remedied by the development and implementation of non-discrimination legislation pertaining to health data in all countries (not only genetic data, as it has become increasingly difficult – if not impossible – to differentiate between genetic and non-genetic data). At the moment this is not a pressing problem in European countries, yet the more different kinds of datasets pertaining to health become available and linkable, and the more predictive DNA data becomes (also in combination with other datasets), the more urgent the need for such legislation.

[89] A participation agreement would consist of two main parts: (1) a mission statement on the side of the biobank (including information on funding and governance, commercialisation, and an outline of what the biobank hopes to achieve; in other words, an insight into the 'value system' of the biobank. It would also include a statement with risks and benefits and a note that this list may not be exhaustive, guided by the value of veracity); and (2) a consent form on the side of the participant (including, where appropriate, an individual risk assessment, and legal waivers).

(Re-)consenting and communicating findings to participants

6.27 It is typically deemed acceptable that participants cannot expect to be contacted directly with the results of the analysis of their individual samples and data, unless these can be expected to have significant health impacts (for an overview see Kaye et al. 2009; see also Johnston & Kaye 2004).

6.28 This does not mean that the option of *all* findings or results being fed back to individual participants should be excluded in principle; there will be contexts where such arrangements may be deemed desirable (see Ormond et al. 2009). Wherever possible, biobanks should make accessible as much data and information as possible, not only to individual participants but to the public (e.g. internet platforms, online data archives etc.). Where results and/or raw data are published open source, research participants should be made aware of these opportunities. Yet wherever biobanks do not serve a primarily commercial purpose, these arrangements should make cost containment an objective. In our view, contacting participants individually with results that are not expected to have significant clinical utility is unduly expensive. For publicly funded biobanks in particular, it should be acceptable that participants who are interested in seeing data and information generated by the biobank take the initiative of accessing the data via online platforms or other repositories.[90] Again this is a cost that reflects the solidarity basis of the biobank model we propose and one that participants (who have already voluntarily agreed to sign up to participate in this research) would have to be – and, indeed, if they agreed, should be – willing to carry in order to assist others they share sameness with.

6.29 Wherever appropriate, agreement to participation forms should also state the willingness of participants to be re-contacted if further details should be needed for subsequent research, although participants would never be obliged to provide these. Wherever reasonably possible, re-contacting should take place by electronic means. Participants would also give their consent for other archived data, held in separate repositories, to be used in connection with the data stored in their biobank, if used in compliance with relevant confidentiality and data protection standards.[91] In many countries this can currently be done without the consent of the participant, yet a participation agreement would include such information explicitly as well, for the sake of honouring the principle of veracity.

A conceptual shift towards harm mitigation strategies

6.30 In our model, significant time and effort would need to go into devising and preparing the participation agreement. However, costs for later re-consenting and re-contacting, and policies to determine under what circumstances findings will be fed back to individuals, could be minimised. Overall, this approach reflects a **shift from focussing resources on risk prevention** (in a context where risks for participants are typically already relatively small) **to devising strategies for harm mitigation in cases where actual harm occurs** (such as discrimination against a person whose data and samples are stored in a biobank by an insurer or employer). As scenarios of potential harm depend on the concrete circumstances of participation in biobank-based research (e.g. what kind of samples, data and information are stored in the biobank? Are they coded or anonymised (Elger & Kaplan 2006), and who can access them?), harm mitigation strategies would best be considered, in general terms, at the time of devising the participation agreement, and be determined in detail when such harm actually materialises. Every biobank should have a committee which can meet on an *ad-hoc*

[90] Commercial companies have put forward the argument that access to individual results should be seen as a right of research participants (for an overview of this debate see Tutton & Prainsack 2011). While we agree, in principle, with the anti-paternalistic thrust of this claim, and we encourage the idea that individuals access and engage with the results, we hold that it is acceptable in the context of publicly funded biobanks that participants waive this right for the sake of cost-containment. Furthermore, it should be noted that commercial companies who grant access to individual results to customers do so because this is their business model (customers pay for access to – and/or interpretation of - their individual results).

[91] The ongoing debate about electronic health records is particularly relevant in this context. For an overview see Kohane 2011.

basis and has the authority to make binding decisions on harm mitigation on behalf of the biobank (e.g. whether and in what form to compensate the person afflicted by harm). A certain proportion of research and/or infrastructure funding that a biobank receives could go into a dedicated fund to compensate participants in the case that they suffer actual harm resulting from their participation in the biobank, if such instances ever arise. This should be underwritten by the funder (see also van Hoyweghen 2007).

The three tiers of solidarity in research biobanking

6.31 The participation agreement that participants sign can be qualified as a declaration of solidarity on the side of the participant, both with the values and the cause of the biobank, and with the people for whom potential benefits might accrue. The main objective of the participation agreement and the process in which it is embedded is to give a potential participant a thorough basis for deciding whether or not she wants to participate. It is an inherent part of the agreement process to communicate that such participation includes risks, and to assess whether these risks are acceptable to the individual in light of the values and possible benefits that the biobank stands for. The overarching goal of this process is *not* to introduce more measures to minimise these risks further, below a threshold that most people deem acceptable (where these thresholds in concrete contexts will need to be explored empirically.)[92] By signing the partnership agreement, the participant confirms that she is willing to carry certain potential costs should they arise.

6.32 Our approach is based on the understanding of solidarity we have developed in Chapter 5, and we have applied it in a prescriptive manner – that is, suggestions are drawn regarding what changes should be made to existing biobanks, and how new biobanks should be governed. This is grounded in the assumption that our working definition can serve as a consensus that is sufficiently strong for it to be used it in such a way. The biobank model we have suggested here reflects solidarity in a threefold manner. Firstly, and reflecting Tier 1 solidarity (interpersonal level), it takes that people are regularly willing to accept costs (the risk of harm and the inconvenience of participation) to assist others based on the perception of similarity. In instances of biobank-based research where the risk of harm remains below a certain threshold, individuals would sign participation agreements where they express their commitment to a certain research endeavour. This entails that they accept certain potential costs, and the scenario of their samples and data being used for purposes other than envisaged originally. However, they assume these costs in order to assist others, and the materialisation of this latter goal would have to be actively worked towards by the biobank. Thus, research biobanks which benefit from solidarity-based participation should put governance structures in place (e.g. via a governance board or trusted intermediaries) that enforce prioritisation of models for access to biomaterials and data that favour research, which serves pressing health needs over research that will achieve the highest profits.[93] Such trusted intermediaries should have real decision-making power rather than merely advisory functions. This would help ensure that the main goal is assistance of others (individuals or populations) via, for example, future health gains, and that solidarity-based research biobanks are not exploited unduly for the purpose of financial gain (i.e. solidarity-based biobanks will most likely be publicly funded).

6.33 Tier 2 solidarity (group level), that is, solidified solidarity practices which are expressed in terms of communal commitments, would manifest themselves in research biobank governance arrangements which envisage research participants as partners in research to whom the biobank owes respect, transparency and veracity. The active contribution of individuals to the

[92] A recent example from the TwinsUK cohort at King's College London showed that when they were required to re-consent 6,000 volunteers regarding a new use for their DNA sequence information, only one per cent did not give consent (personal communication with Tim Spector, director of the Department of Genetic Epidemiology and Twin Research at St Thomas' Hospital, King's College London, 3 June 2011).

[93] We are grateful to Dr Klaus Hoeyer for this suggestion.

biobank is recognised as based on solidarity; the participant and the research biobank are partners in a research endeavour guided by the shared interest to assist others, rather than merely parties in a legal contract. Hence trust, understood as the reliance on someone or something (see Chapter 4) is an inherent part of the partnership between the participant and the research biobank. It commits research biobanks to a kind of conduct that renders them worthy of trust (thus including transparency, respect, and veracity towards their participants and the public); and, consequently, of solidarity. A degree of Tier 2 solidarity could be seen to be already inscribed in existing data-sharing arrangements (granting of access to datasets to other researchers; see also Dobbs 2011), and open access publishing standards.

6.34 Data sharing meets the criteria of Tier 3 solidarity (contractual/legal level) once it is a contractual obligation on the side of researchers (typically when they receive public funding), or when there are legal obligations for making data accessible to others in the public domain, and/or to use open access solutions for the publication of findings (see also Leonelli & Bastow 2010). If research biobanks are to be based on Tier 1 and 2 solidarity, we suggest that data sharing is implemented as such an obligation in all research biobanks governance. Moreover, Tier 3 solidarity where communal arrangements have solidified further into legal arrangements, would be present if the partnership model for research participation found entrance into new ways of thinking about consent in this context.

6.35 Our solidarity-based research biobank model resonates with evidence from empirical research of participants in biobank-based research studies. For example, Simon et al. (2011) recently found in a survey and focus-group based study involving almost 800 respondents in the US that "[m]any individuals want to make an active and informed choice at the point of being approached for biobank participation but are prepared to consent broadly to future research use and to forego additional choices as a result" (Simon et al. 2011). We hope that our model can serve as a step approach towards shifting the focus of discussions and practices in biobank-based research in the spirit of Hoeyer's timely analysis: "it is time to move the debates beyond informed consent and to critically assess what can be done to make biobanks into trustworthy institutions of long-term social durability" (2008: 430).

6.8 Suggestions

6.36 We suggest that solidarity as understood in this report can be assumed in the case of individuals signing up to publicly funded research research biobanks. We suggest that solidarity is used as a basis for redesigning governance structures of future research biobanks, and improving those of existing research biobanks (although this would affect only new participants).

6.37 Based on our understanding of solidarity, research biobanks governance should shift from an approach of risk-prevention to harm-mitigation (in cases where actual harm occurs). This would entail a number of specific changes to governance (see below).

6.38 Solidarity-based research biobanks would have to aim for the overall objective to assist others. Research goals and therefore data use might change, but assisting others would have to remain the ultimate end – not, say, greatest financial profit. Thus, research biobanks which benefit from solidarity-based participation should put governance structures in place that ensure that research serving pressing health needs is prioritised over research aiming to generate surplus value.

6.39 With regard to recruitment, participants would sign an agreement to participate which would not be focussed on specific informed consent, but rather on veracity. Participants would be informed in detail about the mission of a particular research biobank, its funding and governance structures, and what it hopes to achieve. The initial disclosure would also have to include an explanation that research objectives might change and data may be used to serve research that cannot yet be envisaged, and that appropriate research ethics approval will be obtained wherever laws and regulations require this. The disclosure statement would also have to include a list of risks and benefits insofar as they can currently be foreseen, with an explicit note that this list may not be exhaustive.

6.40 As for re-contacting and communicating of results, for solidarity-based research biobanks, it would be acceptable to consider costs of re-contacting participants and to refrain from contacting individuals about information that has no direct individual utility. Furthermore, participants who are interested in seeing data and information generated by the research biobank could be expected to take the initiative of accessing the data via online platforms or other repositories.

6.41 Finally, in order to enable cost-effective and non-bureaucratic mitigation of harms, solidarity-based research biobanks would have to establish dedicated funds for compensation of individuals affected by harm (such as demonstrable cases of discrimination by employers or insurance companies).

Chapter 7

Solidarity in practice II: pandemics and global health - the case of 'swine flu'

Chapter 7 – Solidarity in practice II: pandemics and global health - the case of 'swine flu'

7.1 After a brief introduction about pandemics in general, we focus on the case of swine flu in this chapter. We describe the pandemic of 2009/2010 and some of the problematic issues that were raised during that time. We then explore whether our understanding of solidarity can be mobilised to support arguments for the acceptance of costs that occur when measures to prevent/contain pandemics are implemented. Specific examples include vaccination, triage, surveillance and restriction of mobility. We describe emerging solidarity practices that could be usefully employed in the context of pandemics, and explore how solidarity can be applied to cooperation and assistance between nation states.

7.1 Pandemics: background and current challenges

7.2 While this report was being written, Europe was in fear of a pandemic. Starting in May 2011, an increasing number of people – first in Germany, then also in other countries – came down with infections caused by the enterohaemorrhagic *Escherichia coli* (EHEC) bacterium, which can lead to renal failure. Thousands of people were infected, and more than 50 died. For a long time, authorities were in the dark about where and how exactly the bacterium spread. Early indications pointed towards salad vegetables, which most of the affected patients reported to have eaten prior to falling ill; later on the bacterium was found on organic sprouts in northern Germany. In a communal effort coordinated in online platforms, strains of the bacterium were sequenced; it was found that the particular strain was likely to have resided in humans for a long time until it started to produce the fatal toxins (Turner 2011).

7.3 With Hamburg – a city with a large port – having been the epicentre of the epidemic, it was further assumed that the infected vegetables had come into Germany by ship. When a sample of Spanish cucumbers tested positive for the EHEC bacterium, this prompted millions of people to refrain from buying vegetables, particularly from Spain, which hit local farmers very hard. Spain's Prime Minister Zapatero complained about what he perceived as excessive and hostile reactions towards Spanish producers and called for reparations. Early in June, Russia announced a ban on importing vegetables from the EU (BBC News 2011), again adversely affecting farmers' incomes. Many people were sympathetic with the actions of the German and Russian authorities: it was argued that it would have been irresponsible for them not to take measures of precaution. Further, while the negative effects on Spanish farmers and on the EU economy were regrettable, such costs would need to be accepted in a situation of crisis. Was this an expression of solidarity?

7.4 As this example shows, not only can a pandemic or the fear of it[94] pose a great strain on national governments needing to find ways to contain it, but it can also contain significant costs for 'innocent' people and create tensions in the international community. (As De Grandis Littmann and argue, "[w]hile issues of international cooperation are not exclusive to disease with global diffusion, these latter raise them more acutely" 2011: 5). Pandemics raise the question about solidarity at several levels: at the level of solidarity between individuals and their

[94] As De Grandis and Littmann analyse, pandemics "more than any other kind of disease have a virtual existence apart from having any actual existence. This means that preventive measures are taken against a threat that is unknown. […] Precaution and preparation are carried out on the basis of forecasts, anticipations and modelling and therefore a good deal of policy-making concerning pandemics takes place in circumstances of great uncertainty, in which risks and benefits are highly hypothetical." (2011: 7).

willingness to accept costs to assist others in such a situation; at the level of relationships between individuals and state actors, as the latter may intrude into spheres of individual freedom and decision making for the sake of avoiding or mitigating societal harm; and at the level of relationships between countries (and other global actors). The latter dimension has received attention in the context of debates on global public health and global bioethics.

7.5 As discussed in Chapter 3 of this report, public health can be defined as collective and public measures to enable, maintain and restore the health of people. Because collective and public measures typically need coordination, implementation, and the possibility of enforcement, the role of state authority is much more prominent in the field of public health than it is in other realms of health and medicine. As De Grandis and Littmann put it, "[o]nly states have the authority and power to implement the measures that may contain the spread of disease through the control of the environment and of the host.'" (2011: 5).

7.6 Although we may take this situation for granted – that states have duties to create circumstances and conditions that allow people to lead healthy lives (e.g. pollution control, the availability of clean drinking water, anti-smoking legislation)[95] this has not always been the case. The concern of states for the wellbeing of citizens is intimately linked to the emergence of the modern territorial state (Foucault 1991, 2003; see also Lemke 2011). With these countries becoming increasingly affluent, measures and forms of 'old public health' focussing on infectious diseases and public hygiene seemed to become less important while lifestyle-related diseases (see next chapter) and degenerative diseases started to dominate the agendas of 'new public health' (thus these latter kinds of diseases are sometimes referred to as 'epidemics' of modern times). However, the pandemics as well as the massive natural disasters of the late 20th and the early 21st century have brought the 'old' problems of public hygiene and infectious disease protection back onto the agenda.

7.7 Pandemics thus continue to lie at the core of the state's concern for health in two respects. Firstly, epidemics and pandemics are related to the phenomenon of population clusters: wherever large numbers of people share space, tools, and instruments, or means of transportation, the risk of the spread of infectious diseases is particularly high. Because it has become the task of modern states to regulate public hygiene, organise public transportation, and give planning permissions for housing, the spread of infectious diseases is more closely linked to the efficiency or inefficiency of governmental action than some other disease areas. Secondly, because some infectious diseases have a high mortality rate, and because their spread can pose such a fundamental threat to the population of entire regions, states, or even continents, even people who usually call for governmental restraint from 'meddling' with people's affairs and 'intruding' into individual spheres tend to accept strong governmental action in connection with the containment of contagious diseases. In what other context would people accept that governments restrict the freedom of movement of people (forced isolation), or withhold life-saving medication or treatment from those who need it (triage)?

7.8 The following sections will discuss the extent to which our understanding of solidarity can help to justify or strengthen actions that are considered desirable in the context of a pandemic from a public health point of view. We will use the term pandemic to signify an infectious disease actually or potentially diffusing on a global scale (see De Grandis & Littmann 2011). The term epidemic will be used to refer to infectious diseases when they affect a large number of people in one area in the same time. While this case study will address many questions arising with regards to solidarity in the context of pandemics in general, the concrete point of departure is the swine flu 'pandemic' of 2009/10. We chose this example because it shows the complexities involved in collective and individual decision making in a context of high risks and high levels of uncertainty.

[95] These state duties – and duties of third parties in a society – are conceptualised in the stewardship state model developed in the Nuffield Council on Bioethics' report *Public Health: ethical issues* (NCoB 2007).

7.2 The case of swine flu

7.9 The so-called swine flu received its name from its origin as a H1N1 virus affecting pigs. It became notorious in recent public (health) debates because of the pandemic that the virus caused in 2009 (Trifonov et al. 2009). The World Health Organization (WHO) advised countries to implement their pandemic plans in August 2009 (Chan 2009; Kelly et al. 2011). In August 2010, when the WHO declared the pandemic to have ended, the virus was believed to have caused at least 18,000 deaths (Barry 2011). A very similar virus had caused a pandemic exactly 90 years earlier (the 'Spanish flu', 1918-1920), which had affected nearly the entire world and led to tens of millions of deaths (Harris et al. 2010). Because of the relatively small proportion of the 2009-10 swine flu pandemic compared to the scale that had been expected, national health authorities as well as the WHO attracted criticism from public media for having caused unnecessary panic and disruption; moreover, it was argued that the panic that was created served the vested interests of those who wanted to sell drugs, and to 'justify the WHO's budget' (see Jenkins 2009).

7.10 The alleged 'panic' expressed itself in proposals to close airports and schools, in the introduction of border-screening measures, and in initiatives and recommendations by many national health authorities for people in 'vulnerable groups' to be vaccinated. In the UK, pregnant women, those living with immunosuppressed people (such as people infected with HIV) or those on renal dialysis, and people in the seasonal flu vaccine at-risk groups were contacted by their GPs and offered vaccination (DirectGov 2010). The vaccine used for this purpose was highly controversial in many countries as some claimed it caused a disease affecting the nervous system, the Guillain-Barre Syndrome (GBS). Fears were expressed that more people could die from the vaccine than from the flu itself. The use of the vaccine for children was particularly controversial as the substance had not been tried on children before (e.g. MacFarlane 2009; Smith 2011). In addition to criticism directed towards health authorities for allegedly creating a flu panic, public media were criticised for creating a vaccination panic (Tchuence et al. 2011). In the US, people were reported to have refrained from vaccination because they believed it was not needed, especially at the early stages of the pandemic (see also, for similar data from Japan, Yi et al. 2011, and for Canada, Henrich & Holmes 2011). At the same time, the US Government in particular was criticised for not providing adequate vaccine supplies to the population (SteelFisher et al. 2010; Harris et al. 2010). Whatever the reasons – whether people abstained deliberately out of fear of the side-effects of vaccination, or whether they did not have access to the vaccine – throughout most of the industrialised world, vaccination rates remained low during the pandemic (Velan et al. 2011; Kelly et al. 2011; Harris et al. 2010).

7.11 Vaccination is only one issue where questions of solidarity, which we understand here as the willingness to accept costs to assist others, become pertinent. As we will see, the case of pandemics poses complex challenges to the role of solidarity in both supporting and bringing about desirable solutions in public health contexts.

7.3 Solidarity between individuals, and the relationship between individuals and state authorities

7.12 Solidarity plays a different role in the context of pandemics compared to our first example, research biobanks. As pointed out in the previous chapter, research biobanks express a collective commitment to carry 'costs' (financial, social, emotional, or otherwise) to assist others. Individual participation in biobank-based research can be conceived as an expression of solidarity understood in these terms. This willingness is regularly based upon the recognition of similarity, or even sameness, of a person with one or more other people in a relevant respect. Not only in the context of research biobanks, but in disease research in general, such recognition of sameness can take many forms: for example, signing up to UK Biobank to become a participant based on the recognition that this participation may help many others who, like me, need medical treatment from time to time, or who are afflicted by a serious disease (such as perhaps a relative or friend of mine). These disease risks are relatively generalised

(i.e. most of us share similar levels of risk), span a long period of time (the risks and benefits could materialise over several decades), and the costs incurred for me by my participation in a research biobank are relatively low.

7.13 In the context of pandemics, in contrast, the stakes involved are different, because the risks and costs are distributed very unevenly.[96] Because pandemics span over a relatively limited period of time, and because they do not only affect a sub-group of the population (e.g. compared to those who participate in a biobank) but the population in its entirety, risks and stakes are very diverse: as a healthy young person without children, for example, I may be far less worried about the 'worst case' of contracting this disease than an elderly person, a person with a weak immune system, or a parent (the indicators for whom is at particularly high risk are of course different for every disease). While the perceived risks we act upon in other healthcare contexts span over a longer period of time – such as the risk to ever need a donor organ; the risk of being affected by dementia; or the risk of having a car accident – the time span of a pandemic in comparison is very condensed. Although the risks perceptions[97] of people are clearly inter-related and may be openly inter-dependent (e.g. a person considering that if many other healthy people, like her, refrain from vaccination, this will have a detrimental effect on population immunity), the levels of perceived risks that people act upon within a city region, or country are likely to vary greatly. This applies even if we assumed that people make decisions as 'rational actors', which we know from empirical research that they do not.

7.14 Simultaneously, the potential costs incurred by containing pandemics are typically not limited to relatively small costs (comparable to the costs carried by participants in research biobanks) but they can be very considerable for some people. People at relatively low risk in the context of a particular pandemic may be willing to enact solidarity if the costs are relatively small, such as washing my hands more frequently, or staying at home when I have a fever even if I am not sure whether it is related to the virus causing the pandemic. People expecting to be at low risk may not, however, be willing to accept larger costs, such as not being able to travel by plane, which impedes their work, or to get vaccinated if they believe – rightly or wrongly[98] – that the vaccination itself could have a more detrimental effect on them than the effect of the scenario that it is intended to prevent. This would be the case because people at relatively low risk do not recognise sameness or similarity in a relevant respect with others who are at a much higher risk (sameness in the relevant sense means that we share certain characteristics, risks or stakes with others, see working definition in Chapter 5). For those at high risk, no costs incurred by measures to contain the pandemics may be too high; yet for those at relatively low risk, actions that impose additional risks on them (risk of falling ill from vaccination; risk of losing out on income or opportunities due to the impossibility of getting to work or to travel) may already be too high a cost.

7.15 We believe that because the recognition of sameness with others plays such an important role in fostering solidarity at the level of the individual, it is unreasonable to expect that entire populations – where risks and stakes are very unevenly distributed – will accept the costs of containing pandemics *out of solidarity with each other*. Tier 1 solidarity, to use our terminology, is too weak to support the higher levels of solidarity required for state-enforced action required to control pandemics. In the case of research biobanks, the content of norms could be seen as a 'coagulation' of practices and rules emerging bottom-up from commitments of people to solidarity (in the sense that they accept costs for the sake of assisting others). Thus, in the

[96] See, however, De Grandis and Littmann (2011) for an overview of issues involved in classifying risk, especially at early stages of pandemics.

[97] Throughout this report, we focus mainly on risk perception and risks prompting actions instead of objective risk levels, since we are concerned with shared practices (see our understanding of solidarity in Chapter 5).

[98] The alleged association between vaccination and a range of conditions such as autism in children, and the public health effects that such beliefs have when they make people refrain from vaccination, is a controversial topic that we do not cover in this report. See, for example, NCoB (2007).

research biobanks[99] case, legal norms and policies (Tier 3 solidarity), could to some extent be justified empirically by the existence of corresponding 'voluntary' practices and commitments at individual and community levels (Tier 2 solidarity). This cannot be transposed to the context of pandemics. Although there may be communities at risk comprising those who face particularly high risks in face of a pandemic, the actual or potential costs of preventing these risks affect the entire population which may not all feel solidary with each other (or the at risk group). Hence, policies and legal norms to prevent and contain pandemics are not an expression of solidarity in this instance, but they are an expression of top-down state power, raising issues of paternalism and illegitimate state force in democratic societies.

7.16 This is not to say that people would not, or should not, accept the costs of containing a pandemic; the justification for the authority of state actors to enforce the necessary measures, however, will need to be a different one than allusions to solidarity. At the interpersonal level, thus, pandemics represent a case where the potential of mobilising solidarity to obtain ends that are desirable in a public health context, is limited. We will show why this is the case in more detail below with regards to three aspects: vaccination, triage, and surveillance and restrictions on movement (e.g. airport and school screenings/closures, quarantine, isolation etc.).

Vaccination

7.17 Vaccinations can play an important role in the containment of pandemics (see also NCoB 2007). The main issues related to vaccinations in the context of pandemics are twofold: firstly, especially in cases where a vaccine has not been widely tested, target groups for vaccination may refrain from vaccination because of the risk of side-effects; secondly, vaccination may not be available for the entire population (or all those who want to be vaccinated, or would benefit from vaccination), thus certain groups need to be prioritised over others.

7.18 Regarding the first issue of the fear of side-effects of vaccination (see NCoB 2007: 54-61), it is assumed that people are likely to accept the risk of side-effects only if they believe that the risks of refraining from vaccination outweigh the risks of getting vaccinated.[100] In light of what was argued above, it cannot be assumed that people would be willing to accept the risk of possible side-effects of vaccination purely on the basis of the abstract knowledge that they may, at some point in their lives, also be part of an at-risk group in light of a pandemic.

7.19 Incentives for vaccinations, insofar as they do not stem from practices of solidarity within relatively narrowly delineated groups, usually come from, or have been initiated by, state authorities. Insofar as the recommendations to get vaccinated are targeted at groups of people who would face elevated risks[101] of suffering from the pandemic (those who can be expected to benefit *personally* from vaccination), this could be seen as relatively unproblematic, as the state here becomes active in their own interest (in the worst case this can be seen as paternalistic (Dubois 2011: 7); yet negative consequences from such paternalism are negligible as long as vaccination policies entail recommendations and incentives, and not compulsion or coercion; see NCoB 2007: 57-61). However if recommendations for people to get vaccinated are targeted at larger groups than those at particularly high risk of being affected by the pandemic, then

[99] There is yet another important difference between the research biobanks case and the pandemics case in the context of solidarity, namely the importance and magnitude of what is at stake. The public health impact of the progress of biobanks-based research, albeit surely considerable, would not be as immediately drastic and dramatic as the impact of being unable to take measures against a mounting pandemic. Thus the overall cost and danger of doing nothing in light of a pandemic is much bigger and worse compared to 'doing nothing' with regards to biobanks.

[100] As the NcoB report *Public Health: ethical issues* (2007: 55) states, "most people accept vaccines in situations in which the incidence of a vaccine-preventable disease is high, the disease is potentially serious and the risks from the vaccine are proportionally low." The risks of suffering serious negative consequences from the disease is not the same for everyone; people's compliance with vaccination policies in light of pandemics thus varies partly according to the assessment of these personal risks (as well as with attitudes towards vaccination in general). It should be noted in this context that we assume that people do not only consider risks that pertain to them individually, but also those pertaining to others with whom they are connected in love, friendship or solidarity (e. g. people with suppressed immune systems after an organ transplantation, if a close friend or relative of mine has also undergone an organ transplantation).

[101] In this instance, we refer to risk levels established by public health and other (governmental) authorities.

individuals in low-risk groups may be faced with the situation that – if considering only a short timescale - they would carry the risks of side-effects from the vaccination for the sake of protecting others. In this instance state authorities become active not in the interest of the people that measures are targeted at, but as protectors of other groups of people. The latter kind of measures can neither be justified on the basis of protecting the interests of people at whom the measures are targeted, nor on the basis of solidarity, as was argued above. Such measures could, however, be justified on the basis of referring to the state's (moral and/or legal) duty to protect the most vulnerable,[102] and/or to protect people's right to life, even if this comes at the cost of others. This understanding is not radically new but it is already entrenched in existing legal institutions (for example, a person is regularly not culpable if she takes somebody else's property, or even injures a person, in order to save a life). The state, here, performs protective functions for individuals who could in a given situation not protect themselves alone.[103]

7.20 With regards to the second issue – the allocation of scarce vaccines – regardless of which approaches are chosen,[104] in cases where vaccinations prevent serious harm, any prioritisation of certain groups would disadvantage others and perhaps even put them at risk of death. In this situation, state authorities make decisions which are based on either empirical evidence (e.g. on who needs vaccination the most to survive, or for society to continue to function), or based on certain values guiding the allocation. In a situation of perfect democracy, such empirical evidence, and such values guiding the allocation of scarce resources, would be extensively analysed and discussed, as well as tested for their democratic support (e.g. via public consultations). Crises are, however, situations where state authorities need to make decisions under great time pressure, without the possibility to obtain or assess democratic legitimacy of the values underlying these decisions. Decisions could thus be made which later turn out to have unduly disadvantaged, or put at risk, certain groups. Thus, costs and benefits for all groups involved need to be carried out as thoroughly as possible in the given circumstances, and coercive measures should be avoided whenever possible.[105] Where necessary, careful evaluation of envisaged risks and benefits of a measure has to be performed, and its level of intrusiveness needs to be considered carefully in order to decide on which actions are proportionate.[106]

Triage

7.21 Triage is a method of prioritising patients for treatment in light of limited resources (e.g. material resources, human resources, time). It is, to some extent, part of normal medical care, which always takes place against the backdrop of limited resources, such as personnel time. It becomes more pressing, and more drastic in its effect, in light of crises: for example, in the case of large-scale accidents, wars, natural disasters and also pandemics. In these situations, large numbers of people are affected by a serious problem and in need of treatment all at the same time, and available resources are typically not sufficient to give everyone the care that they require. Thus, mechanisms and models need to be developed which allow the providers of medical care to know which people to give priority to. Triage usually takes two forms: either

[102] For an example of this approach, see Siegal & Bonnie 2006.

[103] If not in the context of a particular pandemic, then on a larger timescale, such arrangements could even be seen as obligations emerging from the value of solidarity, as each one of us could be in need of such 'emergency protection' in the future. In this respect, 'we are all in the same boat'.

[104] For examples, see NCoB report *Public health: ethical issues* 2007: 74, including the prioritisation of the youngest; healthcare workers; key workers, etc; also see WHO 2007: 13-15.

[105] As stated in the NCoB 2007, given the complexities inherent in questions about vaccination, the concept of 'free riders' (i.e. persons who benefit from population immunity, or in our case, the containment of a pandemic due to vaccinations, without getting vaccinated themselves) is not a helpful one in this context. This argument should typically not be used to justify coercive vaccination policies. Situations of catastrophic pandemics where there is an empirically proven efficacy of the vaccine in helping to prevent infections could merit an exception of this general rule.

[106] We follow here the argument in the NCoB report delineated with regards to the "ladder of intervention", NCoB 2007: 41 ff.

withdrawing treatment from people,[107] and/or categorising people into different groups of urgency at the time when they seek treatment. Types of triage could be differentiated further into triage decision affecting patients' access to (a) optimal treatment, and (b) life-saving treatment (see also Emmerich 2011).[108]

7.22 In the context of influenza, patients most likely to die relatively fast from a disease are likely to be prioritised for treatment over those who can be expected to have a higher chance of surviving untreated (or treated later) (see e.g. Woodson nd). Again, this is a situation where it cannot be expected that people will recognise sameness with each other. On the most fundamental level – i.e. the chance of dying – people do not share characteristics, risks or stakes; those who have a chance of survival are dissimilar to those who have a greater chance of dying in a relevant sense. Note that the timescale plays an important role here: the relevant context is the situation as it presents itself at the time of triaging – not some potential shared risks in the future. Moreover, the cost carried to assist others would be the highest imaginable – potential death. Therefore, willingness to carry (even the risk of) this cost to assist others and thus enacting solidarity, cannot be assumed. Like in the case of vaccination, triage cannot be justified by referring to solidarity. The most plausible justification is, yet again, that by imposing standards for triage, state authorities fulfil their duty to protect the most vulnerable.

Surveillance and restrictions on movement (airport screenings/closures, quarantine, isolation)

7.23 Surveillance in the context of pandemics typically entails the "systematic collection, analysis and interpretation of data about incidence and prevalence of infectious diseases, and factors that may contribute to them" (NCoB 2007: 63). These data are collected for the purpose of generating insights into: the speed and direction of disease spread; high-risk groups: compliance with proposed measures etc. At a time when data collections, collation and analysis are becoming faster, cheaper and more collaborative, such activities entail increasingly powerful opportunities for public health (see also the debate about infodemiology, e.g. Eysenbach 2002).

7.24 Traditionally, data collection and/or analysis for the purpose of surveillance in the context of pandemics have taken place mainly in anonymised form. For this reason, the issue of consent was deemed as less pressing than in instances where data are collected or processed in non-anonymised ways (see also NCoB 2007: 63-64). However, this situation shifts entirely in light of the increasing use of online tools to collect and analyse data. It could be argued that data which are already online and not protected by access barriers such as passwords (and that thus are in the public domain) can be legitimately used for surveillance purposes in connection with preventing or containing pandemics (such as how many, and where, people searched for 'flu medication' in a search engine online). Yet possibilities for the identification of individuals in a data-rich environment are also unprecedented, which – as some commentators have argued – renders the notions of anonymity, privacy and confidentiality problematic, if not obsolete (e.g. Bauman 2011). This is clearly an issue in need of further exploration and discussion among scholars, policy makers and publics. To the extent to which risks and harms to groups and individuals that could be (re-)identified against their will as a result of such activities would be limited, it could be argued that such low risks would regularly be deemed acceptable in light of solidarity. However empirical research is clearly needed as to where the limits of acceptable costs can be drawn.

7.25 Surveillance measures also serve the purpose of population stratification into different risk groups – e.g. those who are likely to be more harmfully affected by the disease than others; those who are likely to contribute to a wider or more rapid spread etc. On the basis of these

[107] For example, discharging patients with a worsening prognosis from intensive care to make beds available for those who are likely to benefit more from the treatment. This is also referred to as 'reverse triage', as it reverses a treatment decision already made; see Emmerich 2011.

[108] The so-called "fair innings" argument, according to which every person should have the chance to a 'normal' lifespan, can also weigh into triage criteria, making e.g. age a relevant criterion (WHO 2007: 6).

data – and on the basis of other information about where and how the disease in question spreads – decisions are made that can impact on people's freedom of movement, their work life etc. Yet restrictions to the freedom of movement can also take more extreme forms, such as detention or forced isolation. In the UK, for example, infected individuals can not only be prevented from going to work, but they can be detained in treatment centres (for more details, see NCoB 2007: 65).

7.26 Airport checks and school closures were measures that gained particular prominence in the context of the swine flu crisis in 2009-10. While the former have been critiqued as costly, disruptive and not entirely effective, the latter were arguably even more disruptive to a large number of families who had to deal with knock-on effects (lack of childcare options which forces parents – mostly mothers – to miss work to look after them etc).

7.27 Airport checks and other measures to limit cross-border movement in light of a pandemic raise questions about international solidarity. It could be argued that border checks, with the aim of hindering the entrance of infected or otherwise 'at risk' individuals, are a pragmatic approach to slowing down the spread of pandemics as national borders provide existing infrastructures which can be used to slow down the mobility of people. It could also be argued, however, that in the light of crisis, countries seek to close themselves off so as to avoid importing problems from outside their borders. Given that public health policies and polities are firmly couched into *national* infrastructures (e.g. state authorities in one country cannot issue and enforce norms in another), this national approach to health and security is again understandable from a pragmatic point of view. Yet if it serves the purpose of not only containing pandemics but also of containing resources to avoid sharing them with those outside of national borders, such practices are rendered problematic.[109]

7.28 School-closures and their effects could be construed as playing out mainly at the inter-personal levels (Tier 1). Here, it could be assumed that those involved perceive sameness in a relevant sense – that is being parents of children who might very well get infected by other children. It could therefore be assumed that those involved – i.e. parents – would be willing to carry the costs of school closures. Parents are used to considering these decisions when their child is ill. They regularly decide not to send an ill child to school (as she may have the flu and could pass it on to others), even if it means that they will carry costs in terms of needing to stay home or pay for extra childcare. That they do this can be seen as an indication that school closures will be seen as solidarity-based practices in an analogous manner. This is different for airport and border closures. Here, measures are not based on solidarity in smaller communities, but between *national* communities. We take up this issue below.

New practices of solidarity in light of pandemics

7.29 We have so far demonstrated that pandemics are an area where the fruitfulness of solidarity to justify measures incurring costs in one group to assist others is rather limited. There are, however, a number of new practices emerging that deserve our attention as they partly meet the criteria for solidarity practices, and they give rise to new senses of belonging. An important example here is the use of social media to monitor and predict disease spread; to disseminate useful and up-to-date information; and to provide moral support to people in need. Twitter, the free online mini-blogging site which allows anyone with internet access to share information, links and visual material with an unlimited number of people, has become recognised as playing a particularly important role in this context (Signorini et al. 2011). During and after the devastating Japanese earthquakes early in 2011, and in the context of the democratic uprisings in many Arab countries in the same year, people resorted to Twitter to share information, to call for help, to draw attention to acute problems, and to locate and communicate with loved ones.

[109] This would typically be the case if efforts of countries focus on not letting people in, rather than not letting people out.

The social platform Facebook has played a similarly important role (Muralidharan et al. 2011).[110] Some of these initiatives have become institutionalised, such as HIV/AIDS treatment activism, or the search for missing persons; these examples are clear illustrations of Tier 2 solidarity, expressing a collective commitment to carry costs to assist others (who are all linked by means of a shared situation or cause).

7.30 This does not imply that engagement with social media is always automatically a solidarity-based activity. Critics have argued that social media foster narcissism and self-centredness (e.g. Nathan De Wall et al. 2011; Mehdizadeh 2010). Indeed, social media use has a lot of personal utility for people, and this certainly accounts for its popularity to a large extent. Yet social media can also create social ties between people; they are about *both*, self-care and other-care. By knowing more about others – even those who we do not know personally – these others move closer to us. The use of social media in times of crisis has shown that it is relatively common for people to provide assistance, e.g. by circulating information on somebody's behalf (often a stranger), by organising assistance or support, or simply by giving someone a voice.[111] In the context of pandemics, social media could be used to track the spread of diseases, to disseminate and support public health measures, and to create networks for the collation and analysis of information. Engaging in such measures is linked very strongly with solidarity in two respects. First, it builds upon people's recognition of sameness with others: they share membership in the same community, interest in the same goal, and often share similar risks. Second, participation in such efforts typically incurs low costs for individuals.

7.31 Other ways in which social media, and the internet more generally, have been used, and could still be used more fruitfully, in the light of pandemics include: the use of search engines (e.g. *Google*) to track disease spread by analysing how many and where people add certain search terms (e.g. 'flu' and 'medication'); the crowdsourcing of tasks which are very time consuming for individuals or individual authorities (such as the analysis of large data sets, the annotation of existing or emerging datasets, or the sequencing of a bacterium strain; this was successfully coordinated on an online platform in the context of the recent EHEC crisis in Europe; see Turner 2011); and opportunities for public health measures in the context of pandemics to be more democratic by creating feedback loops to plans for such measures and their implementation on social media platforms. The participation of unaffected people in such endeavours is often – yet not always – an expression of solidarity.

7.4 Solidarity between countries (and non-governmental global actors)

7.32 The existence or non-existence of duties for countries to assist others has been discussed in the academic and policy literature. Some important contributions to this have come from the bioethical literature. Within bioethics, the term 'global bioethics'[112] has been used to mean different things. Ruger (2006: 998-999) distinguishes several traditions of addressing global health inequalities (which have tangible effects on pandemic prevention and containment): most of them assign the main responsibility for providing justice at the level of national states.[113]

[110] The impact of these sites has been so considerable for two main reasons: first, because they are free services which are easy to use even for people who do not have a lot of experience with the internet; second, due to the increasing availability of smartphones. Internet use has so far been difficult and precarious in countries where income levels are low and electricity supplies are erratic. Smartphones, on the other hand, are cheaper than computers, they can be used on a pay-as-you-go basis, and they do not rely on stable electricity supplies. It is via smartphones that internet use is spreading into the less privileged areas of the world.

[111] See, for example, the collaborative efforts of strangers to help find missing children (https://twitter.com/#!/missingchildren), the organization of disaster relief (Zax 2010), or the popularity of charitable giving coordinated on *Twitter* (http://www.blueglass.com/blog/wonderful-ways-twitter-has-been-used-for-charity/).

[112] As Holm and Williams-Jones (2010: 10) note, the term 'global bioethics' has been used in different ways in the literature. For example, it was used to signify a global set of bioethical principles or debates, and to call for a globalisation of bioethical concerns, mainly by paying more attention to health needs of poor countries (e.g. Ruger 2006).

[113] Ruger (2006: 999) argues that Thomas Hobbes and John Rawls, and those who base their arguments upon their work, "ground the obligation of justice in the sovereign nation state; global health inequalities have no moral standing; justice, an associative obligation, is owed only to our sovereign citizens. Both Hobbes and Rawls would require global sovereignty or world government to justify duties and responsibilities of global actors to address global health inequalities" (see also e.g. Heyd 2007).

'Cosmopolitanism' argues that justice is deserved by all people, irrespective of their nationality or geographical location. Cosmopolitanists derive from this assumption both a positive duty of national, supranational, international and global actors to collaborate to provide justice for all, and a much weaker duty of these actors to strive for the avoidance of causing harm (e.g. extreme poverty) (see also Pogge 2002).[114] It is interesting to note, however, that solidarity as an explicit concept does not feature prominently within cosmopolitanist arguments.

7.33 As laid out above, the possibilities of mobilising solidarity to justify measures that are desirable from a public health standpoint in pandemics are limited. This is because the costs of containing pandemics are carried not only by a sub-group but by the entire population of an area or a country, and because pandemics concern a relatively short period of time where we all have very different risks and stakes. However, while this applies to the relationship between individuals, and to the relationship between individuals and state authorities, it does not apply to the relationship between countries. Even if not all countries are affected to the same extent, most countries share the general risk of being affected by a pandemic (or another kind of disaster affecting large numbers of people) and needing assistance from other countries sometime in the future. Thus, it is not unreasonable to assume that countries not immediately affected by a pandemic could nonetheless be seen to share similarity – i. e. risks and stakes – in a relevant sense and therefore expected to practice solidarity with those which are.

7.34 This general argument is complicated, however, by several factors. First, unlike people, countries are heterogeneous actors who do not have sentiments or feelings. Solidarity practices emerge differently between collective entities where decisions are mostly made based on national self-interests, than they do in communities where practices solidify from the bottom up (Tier 2 and Tier 3 solidarity). Thus, we cannot expect that countries will act in solidarity with each other because they recognise similarity with others in a relevant respect and thus feel connected, such as individuals regularly do. Political institutions in most countries are designed in such a way that they are conducive for decisions to be made on the basis of cost-benefit analyses for which the timescale is typically the period until the next election (partly for this reason, political commitment to long-term goals such as counterbalancing climate change is so difficult to achieve). However, even though countries do not have feelings like individual persons, they are similarly interconnected. Although they are not individuals or persons, Tier 1 solidarity can be applied to state actors. Moreover, pandemics do not care about national borders. Acting in solidarity with countries in need of assistance can therefore seem rational from a country's perspective, particularly if a large number of its citizens want it (in this context, the impact of social media should not be underestimated). Finally, policy makers are human beings who are regularly (also) motivated by solidarity with those who need assistance.

7.35 Secondly, although in principle, every country could be affected by a pandemic or another disaster in the future, some are more likely to need assistance from outside than others. Factors such as the size, wealth, political structure and infrastructure of countries all contribute to a situation where some would be more vulnerable in times of crisis than others. Risk factors such as the number of large cities or densely populated areas and the availability of infrastructure and resources play an important role in this context. This might affect the level of sameness that can be construed between countries.

7.36 Finally, mutual assistance among countries in times of pandemics is more difficult to argue for because we do not have a super-government that can issue and enforce global norms. When certain actions are required from individuals who do not provide these voluntarily because they do not feel solidary with those who these actions are intended to benefit, there is always the possibility to oblige (and if necessary coerce) individuals to do so (the tax system is an example

[114] This approach is sometimes argued in connection with Amartya Sen's capability approach (Sen 1985, 1992, 1999). Although health capabilities highlight opportunity, they are sometimes argued to entail a negative freedom from "preventable morbidity and mortality" (Ruger 2006: 999).

for this; it is reasonable to assume that not every tax payer makes her contributions voluntarily because she feels connected to her fellow citizens). However, countries cannot be legally coerced into providing assistance in a similar manner; they can only be pressured by means of political or economic measures into doing or avoiding certain acts, yet this is not a feasible (and as many would argue, not an ethically defensible) strategy to get countries to provide support to others.

7.37 In sum, mutual assistance between countries can regularly not be coerced and needs to be voluntary. However, we argue that applying our understanding of solidarity to nation states and the relationships between them can be helpful to reframe discussions around international cooperation and assistance. In the context of pandemics, in a time of globalised travel, all countries share the risk of a pandemic spreading and involving their territory. Despite significant differences in infrastructure, wealth and the potential need for resources, they are therefore similar in a relevant sense. This sameness should be emphasised when global cooperation is negotiated in case of an emerging pandemic; in other words, the implicit references to solidarity present in many writings by global actors such as WHO should be made explicit. In many instances, especially when the incurred costs are relatively low (e.g. sharing of surveillance data; informing other countries of disease outbreaks so that they can get prepared; see NCoB 2007: 67-68), and/or the benefits are very high (e.g. increasing approval rates of an unpopular government), countries already enact or will enact solidarity with one another; the last swine flu epidemic provides us with many examples of such collaboration (e.g. WHO 2011; Fidler & Gostin 2011). Yet in situations where the immediate benefits are expected to be low and the incurred costs are likely to be high, achieving mutual assistance among countries remains difficult. Invoking solidarity in the way we have demonstrated here, and using this understanding of solidarity to argue for particular international measures, could go some way to support responses to this challenge.

7.5 Suggestions

7.38 Because the costs of containing pandemics are carried not only by a sub-group but by the entire population of an area or a country, and because pandemics concern a relatively short period of time where we all have very different risks and stakes, the possibilities of mobilising solidarity in pandemics to justify measures that are desirable from a public health standpoint are limited. We suggest that due to weak interpersonal (Tier 1) and little established group solidarity (Tier 2), state-enforced measures of public health – which would be enactments of Tier 3 solidarity, such as mandated vaccinations – cannot be argued on the basis of solidarity. Such measures need a different kind of justification, for example the duties of the state to protect vulnerable groups in a stewardship state model. The same holds for triage situations in pandemics. Some measures that restrict movement, such as school closures, can be assumed to play out at the level of interpersonal solidarity and involve sufficient degrees of similarity between actors; they can be argued with reference to solidarity.

7.39 There is increasing evidence that social media tools, such as Twitter or Facebook, can strengthen the perception of sameness between people with whom they would not have come into contact otherwise. Their recent and increasing use in times of crises can be seen as an emerging solidarity practice. Social media could be used in pandemics, for example, to track the spread of diseases, to disseminate and support public health measures, and to create networks for the collation and analysis of information.

7.40 Even though countries do not have feelings like individual persons, they are similarly interconnected. Moreover, pandemics do not care about national borders. Most countries share the general risk of being affected by a pandemic and needing assistance from other countries at sometime in the future. Countries could therefore be seen to share similar risks and stakes, making solidarity as understood in this report applicable on a global level. This could be used to overcome the challenges for global cooperation in the case of pandemics that are due to the fact that countries differ significantly with regards to resources, needs, political and infrastructure.

Chapter 8

Solidarity in practice III: lifestyle-related diseases

Chapter 8 – Solidarity in practice III: lifestyle-related diseases

8.1 This chapter is devoted to the discussion of the place of solidarity in the allocation of healthcare services, exemplified by the example of lifestyle-related diseases. We introduce the concept of lifestyle-related disease briefly, before summarising the discussion on individual responsibility for health, stratification of risk and a number of recent changes to healthcare policy. We then reframe this debate applying our understanding of solidarity.

8.1 What are lifestyle-related diseases?

8.2 There is no universally accepted definition of the term lifestyle-related diseases. This is partly due to the fact that there is no universally accepted definition of the concept of disease in the first place.[115] It is common to subsume under the term diseases that are increasingly prevalent in wealthy nations with affluent lifestyles (they are sometimes referred to as 'diseases of civilisation'). In this tradition, 'lifestyle' refers to behaviour that is detrimental to our health, such as sedentary work and leisure activities (e.g. no physical labour, being a 'couch potato'), high intake of sugary, cholesterol-rich and fatty foods, and high levels of consumption of alcohol (adapted from Buchanan 2011). Diseases commonly associated with such affluent lifestyles[116] are, for example, many types of cancer, asthma, type 2 diabetes, obesity, osteoporosis, and sometimes also depression and certain autoimmune diseases.

8.3 A second approach to understanding lifestyle-related diseases is to focus on what are considered high-risk[117] lifestyles, i.e. those which are more likely to lead to disease or injury. This typically includes health-related consequences of certain kinds of sports (skiing, paragliding etc.); yet the term could also be taken to include all of the aforementioned conditions associated with affluent lifestyles insofar as these can be seen as 'high risk' lifestyles.

8.4 A third understanding takes lifestyle-related diseases to be all those that are more prevalent in older people. This approach is clearly connected to the first tradition, where lifestyle-related diseases are associated with affluent lifestyles, as increasing longevity has been a characteristic of rich countries. Diseases and conditions that are not caused by habits detrimental to our health, but that are associated with merely living longer, such as dementia, artherosclerosis and cancer, could also be made to fit the definition for lifestyle-related diseases, although this is less common in the literature.

Lifestyle-related diseases, resource allocation and individual responsibility

8.5 Resources are becoming increasingly scarce in all advanced healthcare systems. This is due to many factors, amongst these the epidemiological transition towards longevity, continuing medical progress and increasing demand for healthcare. Consequently, questions on how to allocate healthcare resources fairly and efficiently have been discussed extensively over the last two decades. A substantial part of this debate is devoted to the questions of whether individual responsibility should be used as a criterion to allocate – or ration – healthcare resources (for an

[115] Concepts of disease range from purely descriptive to normative ones, and from those based on 'normal species functioning' to those based on happiness or life goals. A number of different concepts of health and disease are discussed for example in Humber and Almeder 1997 or in the *Stanford Encyclopedia of Philosophy*: http://plato.stanford.edu/entries/health-disease/.

[116] 'Affluence' here refers to the level of wealth within a society; in fact, the behaviour described is less prevalent in wealthier groups in affluent countries.

[117] An alternative, and arguably complementary, understanding of risk would be, as Mary Douglas (1986:19) put it, to view discussions about risk management as attempts "trying to turn uncertainties into probabilities" (see also Haggerty 2003; O'Malley 2003). By rendering something that is uncertain into something quantifiable and thus tangible, it is brought into the realm of the manageable.

overview of literature and some of the main arguments in this debate see for example Rosen et al. 2010, Schmidt 2009, Buyx 2008, Minkler 1999).

8.6 Those who suggest individual responsibility as a rationing criterion in healthcare almost always refer to lifestyle-related disease in some way. For example, some argue that the treatment of conditions based on lifestyle and health behaviour should be excluded from publicly funded health care or insurance plans, and there are policies already in existence that use financial disincentives to deter unhealthy lifestyles (examples in Schmidt 2008a, Buyx 2008, Bishop and Brodkey 2009, Steinbrook 2006).

8.7 Using individual responsibility and the concept of lifestyle-related diseases in order to exclude patients from free or all publicly funded healthcare, reduce insurance coverage based on health behaviour, or levy fines, is based – whether explicitly or implicitly – on risk classification and risk stratification. No matter which of the concepts of lifestyle-related disease sketched above is chosen, the exclusion is based on the assumption that those excluded have a higher risk of contracting a particular illness (e.g. diabetes type 2 in an obese person), or an overall higher risk of illness. This higher risk is then often linked to cost, meaning that some people with a particular lifestyle incur higher costs for the system than others (see e.g. Stock et al. 2010).[118]

8.8 The attribution of higher risk[119] based on individually chosen lifestyle is problematic, as it is based on direct causal links that are challenging to prove. This is not to diminish the importance of behaviour as a factor for illnesses such as diabetes, stroke, heart failure etc. Available data from epidemiology and public health research shows very clearly that behaviour is a major causal factor in these and many other diseases. However, it is far more difficult to determine exactly what led to a particular condition in an individual patient. For this reason alone, individual responsibility has been rejected by many as a basis for allocating healthcare resources. Moreover, most lifestyle-related diseases are multi-factorial. Recent research in genetics and genomics has shown that almost every condition or disease is the result of a complex interaction of heritable and non-heritable factors having to do with people's lifestyles, social and natural environments etc. Very few diseases or conditions have no genetic dimension at all,[120] and hardly any diseases are caused only by genetic or chromosomal factors (notable exceptions being Huntington's disease or Down's syndrome). Moreover, research in epigenetics has shown that some environmental influences, such as the consumption of particular foods, can change the way genes are switched on or off, leading to a situation where the social is effectively folded into the genetic, and vice versa. Thus, it has become increasingly difficult to differentiate between the genetic – that which has been 'given' to us – and the non-genetic – that which has been 'made' by us or other humans (Keller 2010). Against this backdrop, the notion of what we can be held accountable[121] for, has become a moving target. What if an obese person has a genetic predisposition to not being able to feel when she has eaten enough, can we hold her responsible for overeating (Epstein et al. 2007; Felsted et al. 2010; Grosshans et al. 2011; Bruce et al. 2011)? And what about a couple whose child is born with a

[118] However, as Buchanan (2011: 19) notes, "there is increasing convincing evidence that the total costs of treating people with unhealthy lifestyles over a lifetime is less than the total for healthy people (because unhealthy people die younger), it is equally clear that, on annual basis, unhealthy people use more medical services."

[119] The idea that affluent lifestyles are 'high risk' lifestyles is curious if one thinks of all the health risks that people in non-affluent societies face: malnutrition, lack of hygiene, physical and sexual violence etc. From this perspective, lifestyles in affluent societies are associated with far fewer and also less serious health problems than those in non-affluent societies. The difference between the two situations, though, is that diseases affecting people in non-affluent societies remain untreated (or not sufficiently treated) more often than in affluent societies, and they lead to death more often than in affluent societies.

[120] Even fractured bones due to accidents could be seen as having a genetic component, as some people's bones break more easily than the bones of others.

[121] As Schmidt (2009: 23) points out, responsibility and accountability are not the same thing, as in some cases we regard people as responsible yet not accountable for something (an example that comes to mind would be child who kills an animal because it does not fully understand that an animal feels pain). In rare cases, we also hold people accountable for things that 'common sense' says they are not responsible for (Roussel 2003: 134 gives the example of a mayor in France who could be sentenced for homicide because of a child who was electrocuted with a lamp post which had been put up 20 years before the mayor came to office and without his knowledge).

severe heritable disease, should we 'blame' them for not having undergone carrier testing before conceiving, or for not having aborted the pregnancy?

8.9 In addition, as Schmidt (2009: 130) argues, discussions about responsibility for health and disease tend to "distract the attention of policy makers away from addressing the underlying and hugely important social determinants of health".[122] This line of argument stresses that health behaviour cannot be taken as subject to individual choice only,[123] but rather is shaped significantly by upbringing, education, wealth and many other social and environmental factors. Responsibility, in the context of lifestyle-related diseases, has been been described as a moving target and as ethically and politically problematic (see e.g. Ashcroft 2010).

8.10 Notwithstanding these criticisms, we are currently witnessing a widening of the range of scenarios and situations for which people are seen as (at least partly) responsible. The process of rendering individuals responsible for their health (Rose 1996; 2006) has been extended to include: those who have known family histories of diseases and refrain from taking additional precautions (e. g. a woman with a family history of breast cancer who does not comply with the screening programme arrangements for her mammograms); those who forego susceptibility testing or other predictive testing which is available to them (e.g. if the same woman decides against taking a genetic test to see whether she carries a mutation); and sometimes even those who do not take active steps towards learning more about their individual risks. In a recent report on personalised medicine by the Nuffield Council on Bioethics, this process has been called "responsibilisation" (NCoB 2010). In its extreme form, the responsible individual is seen as one that actively seeks to learn about as many risks as possible so as to take precautions to prevent them from materialising.[124] Being responsible does no longer mean that one avoids activities that are known as excessively dangerous, but it has become synonymous with taking precautions. This understanding, albeit in a slightly different and more moderate form, also resonates with contributions to the debate on lifestyle-related diseases that place emphasis on people's willingness to try to lead a healthy life, even if they do not succeed (e.g. Buchanan 2011, 21: "it is the effort, not the outcome, that counts"; see also Feiring 2008).

Solidarity and risk stratification

8.11 Solidarity, understood as the commitment to carry costs to assist others, is very relevant to this discussion. If people incur higher costs because they are struck by disease due to factors that are considered to be beyond their control (e. g. a person who has always protected herself from the sun suffering from skin cancer; or someone is hit by a car when crossing the road on a pedestrian crossing), then this situation results from a risk that most people recognise from their own lives: We could all be afflicted by such accidents, diseases, or other kinds of suffering that we could not reasonably have protected ourselves from. This situation represents one of the basic vulnerabilities of human and social life.

8.12 If, on the other hand, people suffer from diseases or conditions as a result of deliberate actions, or actions against better knowledge – such as smokers or overeaters are seen to do, or those

[122] There is an extensive body of literature available on social determinants of health; a recent contribution offering an overview of much that has been published is Venkatapuram 2011.

[123] This is also one of the main objections to the arguments of luck egalitarianists (see e.g. Cohen 1989; Roemer 1994; Arneson 1997; Dworkin 2000; Cappelen & Norheim 2005), who argue – in a nutshell – that people deserve assistance only for situations that they cannot be held accountable for, i.e. that do not derive from 'irresponsible' choices. A prominent opponent of luck egalitarianism is Normal Daniels (1985: 2008). For an overview of libertarian and communitarian usages of individual responsibility for health as a rationing criterion, see Buyx (2008: 871).

[124] As Ericson and Doyle (2003: 7-8; see also Green 1997) argue, the process of putting responsibility for risks on the individual is also exemplified in the shift of the moral meaning of the term 'accident': "The word 'accident' is a moral term, denoting that the event in question was not motivated by bad intentions. The event is instead deemed to have arbitrary causation, to be unique and unpredictable. Thus no one can be held responsible for it. Indeed, those involved are victims who deserve sympathy and compensation. However, with the risk of risk discourse, 'accident' is being replaced by other terms that allow the attribution of responsibility. For example, vehicle insurers substitute 'collision' or 'crash'. This new moral language is accompanied by claims that over 90 per cent of all 'crashes' result from individual driver actions." See also Roussel 2003; Hunt 2003.

who drink too much alcohol – rather than having become the victim of disease 'innocently', they are taken to be accountable and indeed responsible for their condition. Our personal understandings of who we are connected with (in the sense of recognising similarity in a relevant respect) shape our judgments of what situations people should be held accountable for (see also Hacking 2003; Garland 2003; Douglas & Wildavsky 1982). For example, if we feel pressured by our social and political environment to undertake every possible preventive and predictive measure to learn about and decrease existing risks, and if we invest money and time and effort in this, we may feel a grudge against those who spend their time and money in more pleasurable ways. We are unlikely to recognise sameness with them and may even resent them. As a result, we feel that we are literally in a different 'category' than those who 'do not care' about protecting their health in the same diligent way that we do. We may feel entitled to lower insurance premiums, as we actively work towards decreasing our risk; or we may feel that we should contribute less into solidaristic insurance arrangements because we already also invest so much in at least our own, individual health. This, in a nutshell, is a reconstruction of an argument that applies our understanding of solidarity in order to justify exclusion or penalisation of lifestyle-related diseases. Sameness in a relevant respect, necessary for Tier 1 and consequently all higher levels of solidarity, is denied, because those who display unhealthy lifestyles are perceived as not sharing common characteristics and risks – at least not enough to warrant solidaristic practices. Thus, it is perceived to be warranted to exclude them from solidaristic practices that play out on a higher level of institutionalisation (Tier 3): namely, for example, from publicly funded healthcare, or from (public or private) health insurance.

8.13 However, what may not be considered in this argument is that, although we may actively work towards decreasing some risks that we know we face, we may have much higher risks in other aspects of our lives that we are not even aware of. As the pandemics case study (see the previous chapter) has shown, the shorter the period of time that we look at, the more diverse people are regarding the risks that they see themselves as facing.. A similar observation applies to the area of lifestyle-related diseases, yet in respect of a different dimension: it is not time which is the decisive factor for our own assessment of risk here but the size of the group against which we compare ourselves in our risk assessment. If we compare the inherent risks of our lifestyles only with those few who live in our house, then it may be possible to list, rate and assess most of the aspects where everyone has increased or decreased risks, and to stratify all people according to whether they have low, medium, or high risks in relation to their health (if only five or six people were involved, this would still be a massive undertaking, as indicators as diverse as diet, exercise, genetic predispositions, pre-existing conditions, overall happiness, social environment etc. would need to be considered). If, however, the group against which we compare our own risks were a larger population, perhaps even an entire nation, then it becomes immediately apparent that we are unable even to begin stratifying people into different risk groups with respect to health in any empirically justified way.

8.14 Moreover, if contrafactually, a risk stratification that included all risks was possible, this would quickly show that singling out the risks attributed to lifestyle-related disease constitutes a problematic bias. As mentioned above, there are so many risks in our daily lives that picking on behavioural risks related to health only cannot be justified. The stratification of populations according to a particular list of lifestyle-related diseases is inevitably arbitrary as it excludes some areas where people's individual risk could be very different from the areas upon which the stratification focuses. Our neighbour with a heart condition may be high-risk in this respect, but low risk in others; and although we eat healthily, exercise and do not smoke, we may eventually get a condition which will ultimately cost the healthcare system much more than the neighbour's heart problem. In other words, risk stratification is always limited by what we know, and what we can know, about risks; and the very characteristic of risks is that they are often not foreseeable.

While private insurance systems operate with risk stratification models, there is much to be said in favour of public systems which limit stratification to a minimum.[125]

8.15 Risk stratification, of course, is not an invention of the 21st century: the stratification of people into those facing, or representing, higher risk vs. those facing or representing lower risks has always been an inherent part of administrative bureaucracies, and can be found in many areas outside of health. For example, criminal identification technologies such as anthropometry and dactyloscopy (fingerprinting) emerged in the 18th century as a tool for the recognition of habitual criminals and thus to separate riskier populations (which were often literally locked away) from the less risky people (Cole 2001). Most famously and perhaps most prominently, risk stratification techniques have been used within insurance (Ericson & Doyle 2003).

Risk stratification in health policy

8.16 What is new, however, is how widely risk stratification has been employed in actual healthcare and insurance policy. The discussions about excluding people choosing 'high-risk' behaviours from solidaristic insurance arrangements (e.g. by charging higher premiums) as discussed above have been a rather recent development, yet there are many examples of how these discussions have already been translated into policy in most developed countries. Dubois (2011: 4) provides an overview of existing modes of discriminating between people with 'healthy' vs. 'unhealthy' lifestyles:

a In the US, there is a trend towards more risk stratification in private insurance (Robinson 2004), primarily along the lines of smoking and body mass index (Kertesz 2006). Simultaneously, there has been an increase in policies relying on co-insurance and deductibles (Robinson 2004), or incentive-based plans and bonus systems rewarding 'healthy' lifestyles or participation in prevention programmes (Heffley & Miceli 1998) (see also Schmidt 2007b).

b In Europe, where healthcare relies overall less on private health insurance, the individualisation of the responsibility of risk is reflected in the rhetoric of the 'active' welfare state (Pestieau 2006; Esping-Anderson et al. 2002; Kemshall 2002; International Social Security Association 2007). In this form of welfare state, people are supposed to not be "passive' recipients of money and other support but rather 'active' contributors to society. A contribution to society in this context is recognised as 'active' if it helps the government to save costs (e.g. by doing volunteer work, caring for family members or friends etc).[126] Despite the intense discussions of the concept itself, as Tinghög et al. (2010: 203) summarise for Europe, 'individual responsibility ... is rarely articulated or used as a rationing principle in the health-care context" in actual policy. They note that the Netherlands is the only country where individual responsibility has been explicitly implemented in policy as a parameter for healthcare rationing (see e.g. the NL Government Committee on Choices in Health Care, 1992.)[127] However, risk stratification based on behaviour seen to be governed by individual responsibility is present in many European healthcare systems. The Swedish public healthcare system does not use individual responsibility within its matrix for priority setting; however, the priority lists and their ranking of treatment-condition pairs reflect that such individual risk stratification has taken place during ranking (Buyx 2008; see also Swedish National Board for Health and Welfare 2004 for cardiac care and subsequent publications for other areas of care). Healthcare systems in other countries, such as Germany, employ bonus

[125] This is of course not to say that measures should not be taken which are conducive to people recognising that although they may carry lower risks than others in some respects (by living healthily, by refraining from dangerous sports etc.), they may carry higher risks in others (by being a unconfident driver; by being highly stressed; by using the car a lot)

[126] As Serrano Pascual (2007: 23) argues, the idea of the active welfare state aims at making people develop or enhance "moral skills, such as self-management, self-help and self-reliance, in order to create a new kind of worker who is more flexible, responsible and active" (see also Holmqvist 2010).

[127] The Dutch proposal envisaged individual responsibility to be "a final gate-keeping criterion" (Tinghög et al. 2010: 203) in regulating access to health services, as the fourth of the following criteria: is the treatment necessary; is it effective; is it cost effective? Can the service be made the responsibility of the individual (c.f. Tinghög et al. 2010: 203)?

systems as incentives and rewards for 'responsible' behaviour in the context of health (such as taking part in prevention programmes, see Schmidt 2008a). Furthermore, Germany also refers to individual responsibility for health on the programmatic level, namely in the German Social Security Code (*Sozialgesetzbuch*) which regulates statutory healthcare.[128] However in the German case, there is no explicit link between individual responsibility and lifestyle, arguably because individual responsibility is understood in a very narrow way: only situations where a disease or injury is attributable to starkly objectionable behaviour that is outside of the range of behaviours tolerated by society, are the consequences seen as in the realm of individual responsibility of the ill or injured person (e.g. if a healthcare need stems from a person's engagement in criminal behaviour, see Schmidt 2008a: 201). Thus, lifestyle 'choices' within the range of what is seen as socially tolerable (including stigmatised behaviours such as smoking) are not seen as factors that people should be held accountable for in the context of public healthcare. Recent discussions in German public media and amongst physician organisations, however, potentially signal that this could change in the future.

8.17 In the UK so far, individual responsibility for lifestyle choices has not yet been proposed to become a criterion for priority-setting in healthcare.[129] The Marmot Review (Marmot 2010: 9), the result of a strategic review of health inequalities in the UK, rejected a focus on individual responsibility in the context of health inequalities and noted that "[h]ealth inequalities result from social inequalities. Action on health inequalities requires action across all the social determinants of health". A recent court case[130] affirmed that the NHS does not appeal to individual responsibility or other social principles. Mr Condliff, a morbidly obese diabetic, was denied funds for his gastric bypass surgery by his primary care trust (PCT) on the grounds that his BMI was 45 points instead of 50, the PCT's threshold for funding surgery.[131] Mr Condliff sued the PCT citing exceptional social circumstances. The case led to considerable media interest, highlighting, among other things, that Mr Condliff could not be held responsible for his being overweight as it was a result of his diabetes. The court was expected to either rule in favour of the PCT based on Mr Condliff bringing his illness upon himself, or against the PCT, arguing that Mr Condliff did not have individual responsibility for his state of health, something which he had always claimed.[132] In the end, the decision did not hinge specifically on whether Mr Condliff was responsible or not. Instead, it was confirmed by the court that the PCT was justified in not responding to claims of exceptional social circumstances that were based on non-clinical factors. The court noted that the process of resource allocation within a system constrained by finite resources requires hard choices because decisions to invest in some categories of care may require disinvestment from others. The court acknowledged that these are difficult decisions for NHS commissioners to make. PCTs must treat patients fairly and equally by using a consistent framework. Individual funding requests should be considered within such a framework which was entitled to exclude non-clinical circumstances. The PCT had adopted these procedures. It had responded to Mr Condliff's needs fairly and consistently with

[128] Article 2 in Book V of the German Social Security Code reads as follows: "Services ... are to be provided by the sickness funds with due respect to cost effectiveness ... and insofar as the need for services is not attributable to the personal responsibility of the insured person" (c.f. Schmidt 2008a: 200).

[129] Although a proposal by the British Medical Association for a Charter on how individuals should behave responsibly as recipients of publicly funded healthcare (and what they can expect from the NHS in return) has created controversy (Schmidt 2007a).

[130] We are indebted to Professor Chris Newdick for bringing this case to our attention and for significant parts of the case description.

[131] The threshold according to (non-binding) NICE guidelines is 35 points.

[132] Mr Condliff's condition was caused by a variety of factors, including type 2 diabetes and severe needle phobia. As a result his insulin was not always provided effectively and his diabetes became worse. Following a course of insulin delivered in an acceptable way, he developed a gross appetite and gorged himself. He lost control of his weight and became morbidly obese with a BMI of 45. He soon developed other illnesses such as renal impairment, hypertension and obstructive sleep apnoea. As a result, Mr Condliff had to start using a wheel chair and became effectively housebound. He became depressed and withdrawn and unable to attend church. He suffered incontinence and could not wash or dress himself, and he relied so much on his wife that she scarcely dared to leave the house.

other patients, without discrimination or disrespect, and did not contravene Article 8 of the European Convention of Human Rights.

8.18 Indeed, as discussed above, there are ethical and practical difficulties in using individual responsibility, or 'social' factors, in decisions on resource allocation. Ethically, such considerations could include a presumption that lifestyle-related diseases arise from free choice for which the individual alone is responsible. The danger is that 'social' reasons could be used to penalise people for suffering from 'lifestyle' diseases. However, diseases caused by poor diet and lack of exercise are most common amongst the least well-off in society. Does this community 'freely' expose themselves to these risks? Or are some people's lives subject to pressures and constraints that are less prevalent elsewhere so that the notion of 'free choice should be modified in this context?

8.19 In addition, how would a system that considers lifestyle 'choices' in processes of resource allocation work in practice? Principles of fairness between patients would require a consistent list of the 'lifestyles' about which social judgments would be relevant. What would be on the list, and who would decide? Would we include the sporting injuries suffered by Olympic hopefuls? What if a patient suffered from a 'lifestyle'-related disease which was, as discussed above, *compounded* by genetic factors? (Mr Condliff's illness may have been such a case.) Would that factor be discounted and if so how? And what if the patient suffered co-morbidities consequent upon their disease (e.g. blindness resulting from type 2 diabetes)? Would that condition merit treatment but not the diabetes?

8.20 The Condliff case illustrates the dangers involved in using 'social' factors as a basis for judgments about access to health care. Although it is easy to see why Mr Condliff's case is extremely painful for Mr Condliff and his family, the stance of the PCT to not pay for Mr Condliff's gastric bypass surgery is to be supported from a solidarity-focussed perspective. Admittedly, the differentiation between clinical and non-clinical criteria put forward by the PCT contains an element of arbitrariness: the label of obesity alone, like many other diagnoses and clinical categories, contains social value judgements and moral meaning, and is somewhat culturally contingent; thus the claim that non-clinical parameters do not weigh into the equation is problematic.[133] Yet against the backdrop of limited resources, saving on bureaucracy (and routinely investigating the claim for individual exceptions) is the best possible way to work towards maintaining a universal and publicly funded healthcare system. Thus, the range of criteria against which claims for individual exceptions will be considered should be kept as narrow, standardised, and transparent as possible. The following section will argue in more detail why this is not only a reasonable approach in the context of the aim of cost-containment, but also an enactment of solidarity.

8.2 Population stratification for lifestyle 'choice': a solidarity-based approach

8.21 Some argue (implicitly) that people who 'choose' unhealthy lifestyles breach their commitment to solidaristic arrangements by placing undue burdens on the collective.[134] This argument is analytically problematic, because, as discussed above, the notion of responsibility in connection with lifestyle 'choice' is a moving target: it is impossible to draw a clear line of separation between situations that people have chosen deliberately (and for which they should therefore be held accountable, as some argue), and situations that 'fate' or other factors have imposed on people's lives (see also Tinghög et al. 2010). Moreover, focussing population stratification on risks in one context inevitably disregards risks in other contexts which may not even be visible or determinable. Thus, risk stratification according to personal responsibility and lifestyle 'choice' would likely lead to greater injustice in healthcare delivery.

[133] It should however be noted that a BMI of 45 points, as in Mr Condliff's case, would lie outside the sphere of value judgement; it is very high and it is impossible to avoid serious health consequences in this situation.

[134] As Tinghög et al. (2010: 201-202), for example, put it, a "fundamental objective of tax-funded health-care is to grant universal access to public health-care services and make it affordable at the point of use. This implies not only a public obligation to improve health, but also to protect people from the financial costs associated with treating poor health."

8.22 For these reasons, in the context of publicly funded healthcare systems, population stratification should refrain from taking into consideration factors of risk stratification and individual 'responsibility' for health problems and conditions. Because publicly funded healthcare systems comprise large numbers of people, 'lifestyle-related' risks to health are likely to be balanced out by other risks that cannot be rendered visible or determinable by looking at lifestyle ('choices'). Thus, expressed in the language of solidarity as developed in this report, there is no basis on which to justify that some people or groups are considered not to be similar in a relevant sense (with regards to risks) to others in the healthcare system. There is an important difference here to both previous case studies: sameness in the relevant sense in the biobanks case was based on a relatively narrow shared context, and in the pandemics case on one particular risk – contracting the infectious disease. However, the lifestyle concept and the idea of personal responsibility for health, if used to claim a violation of solidarity and to deny resources, constitute an arbitrary choice amongst a myriad of risks that affect health, including many social and environmental factors entirely out of the individual's control.

8.23 A solidarity-based approach would instead mandate that access to healthcare should be granted on the basis of need, as need is a category in which sameness in the relevant sense is easier to see than in lifestyle risk stratification. The crucial question, then, is how need is to be quantified and measured. The existing model that combines the expected clinical benefit with an application of universal rules, which are unfavourable to individual exceptions, is not perfect. However, it is arguably the least unfair system possible in light of limited resources. Publicly funded healthcare systems, which are accessible to all residents irrespective of their personal situations and circumstances, are not only desirable from a humanitarian point of view but they also perform well on health outcomes (e.g. WHO 2010).

8.24 A solidarity-based approach would strive to maintain a system such as that in the UK without significant increases in the need for tax contributions. However, in order to do so, costs need to be contained. These should be saved in administration and bureaucracy rather than through the reduced provision of 'frontline' services – an obvious argument. Moreover, it would also be necessary to disincentivise the granting of individual exceptions such as the one asked for in the Condliff case. This would mean reversing a trend apparent in many developed healthcare systems, where individual exceptions are increasing and physicians prescribe interventions, sometimes off-label, on patient request.

8.25 This approach is in line with our working definition of solidarity which understands solidarity as shared practices reflecting a collective commitment to carry costs to assist others. At the interpersonal level (Tier 1), solidarity comprises manifestations of people's willingness to carry costs to assist others with whom a person recognises similarity in at least one relevant respect. As the Condliff case has shown, individuals who are negatively affected by the application of general rules will not always accept this situation on the basis of solidarity with others, because they feel they are being treated unfairly. This problem can be mitigated in two ways. First, there could be hardship funds for demonstrably exceptional cases and those put in danger by the application of existing rules. Such hardship funds could be resourced by civil society/charitable organisations outside of the public health care system.

8.26 Moreover, a higher appreciation of the importance of preventive and public health measures, both when allocating resources and in public perception and understanding, would be desirable. For this, there needs to be a shift in public discourse from individual responsibility for health towards mutual assistance in health. In situations where a person is affected negatively by the application of a rule in the context of access to certain health services, it is much more likely that she will accept the situation or look constructively for alternatives if she accepts the general values underpinning the system and if she sees what she shares in common with other people within the system. Instead of providing incentives for people to respond to rule-application in a short-term perspective by focusing on one particular instance of perceived injustice, we should facilitate long-term perspectives which emphasise that, over a longer period of time, the groups of people who are disadvantaged in one particular context will be advantaged in another (see

also Stone 1999). This would require broader recognition in the population of the sameness we all share when it comes to health risks. Currently, much of the public and political discussion on risk stratification and individual responsibility serves to focus arbitrarily on one particular group of risks, whilst disregarding many others. It would instead be helpful, if a solidarity-based approach is desired, to strive towards a debate underlining that risks for health are much broader and we all face them.

8.27 A stronger emphasis on similarities and shared commitments would for example involve a focus on public health, due to its inherent reference to collective risk- and benefit sharing (see chapter 3). Stories about single individuals saved by miraculous high-tech medicine are typically more interesting to the media; nevertheless, positive narratives about preventive medicine and public health can be told as well. Recently, a new emphasis on collaboration and community has emerged from open science and participatory health initiatives, where people – patients, students, even online gamers – work together to solve problems and develop tools and technologies to improve health (e.g. Khatib et al. 2011; Wicks et al. 2011; Nielsen 2011). The wide attention that such initiatives have received provide a positive example for how better health outcomes could be achieved not by focusing on the rationing of services and the penalising of 'deviant' behaviours, but by crowdsourcing the quest for new solutions.

8.28 Finally, it would be preferable to call for active and healthy lifestyles in a positive way, as joyful ways of living.[135] And many people may respond positively to the argument that more active lifestyles are one factor that helps support the shared commitment to assisting each other via a public health care system.[136]

8.3 Suggestions

8.29 We suggest that proposals to assign the allocation of healthcare resources on risk stratification based on the concepts of lifestyle and individual responsibility is problematic for a number of reasons. These include: the difficulty of determining causality; the trend to ever greater responsibilisation of risk; and the arbitrariness of focussing on a class of health risks (i.e. behavioural) and not the many other classes (social, environmental, genetic etc.) that affect our health.

8.30 Seen through the prism of solidarity, appealing to personal responsibility to penalise or exclude people from publicly funded healthcare or insurance amounts to an unwarranted denial of sameness. Sameness in a relevant sense is denied, because those who display unhealthy lifestyles are perceived as not sharing common characteristics and risks. However, we argue that this is based on a biased, narrow focus on behavioural risks only. Consequently, the penalisation or exclusion of people from solidaristic practices on higher levels of institutionalisation, such as from publicly funded healthcare, is not justified.

8.31 Many developed healthcare systems already include explicit or implicit uses of lifestyle-based risk stratification in health policy and resource allocation. In addition, there is a trend of increasing numbers of individual exceptions and prescriptions on patient request. The UK is so far an exception, since in the NHS, non-clinical criteria in general do not underpin the allocation of healthcare, and individual exceptions are regularly not granted.

8.32 We believe that from a solidarity perspective, this should remain the case. Moreover, we believe that foregoing individual exceptions from general rules can be seen as a contribution to preserve the shared commitment to assist each other via the preservation of a publicly funded healthcare system where allocation is based on need.

[135] A healthy diet and moderate exercise that a person truly enjoys, for example, have been show to have many benefits for mood, self-esteem and the perception of control in one's own life (e. g. Minkler 1999).

[136] The idea of the 'Big Society' appeared to appeal to collective engagement in a positive way when it was introduced and before it was used for political campaigning. It is currently widely regarded as an almost cynical label for cost-cutting.

8.33 Finally, we would welcome ways to facilitate a shift in public discourse towards a stronger emphasis on similarities and shared commitments. We recognise that social media can be particularly powerful in this context. In addition, many open science and participatory health initiatives provide exciting examples of enacted solidarity on the side of its participants, who volunteer time and efforts to collaborate on developing innovative ways to improve health. The potential of such initiatives, which have so far been below the radar of many funding agencies and health authorities, should be utilised and supported.

Appendices

Appendix 1: Workshops and participants

1st workshop: 'Solidarity as a core value in contemporary bioethics', 13 May 2011, NCoB, London

1. Professor Richard Ashcroft, Professor of Bioethics, Department of Law at Queen Mary, University of London
2. Dr Alena Buyx, Assistant Director, Nuffield Council on Bioethics
3. Professor Ruth Chadwick, Distinguished Research Professor, School of English, Communication and Philosophy, University of Cardiff
4. Dr Kathryn Ehrich, Research Fellow, Innovations Programme, NIHR King's Patient Safety & Service Quality Research Centre, King's College London
5. Nathan Emmerich, PhD Candidate in the School of Sociology, Social Policy and Social Work, Queen's University Belfast
6. Tom Finnegan, Research Officer, Nuffield Council on Bioethics
7. Professor Robin Gill, Professor of Applied Theology, University of Kent, Nuffield Council on Bioethics member
8. Dr Darryll Gunson, Lecturer in Politics and Sociology, School of Social Sciences, University of the West of Scotland
9. Shawn Harmon, Research Student, School of Law, University of Edinburgh
10. Kate Harvey, Research Officer, Nuffield Council on Bioethics
11. Varsha Jagadesham, Research Officer, Nuffield Council on Bioethics
12. Dr Jyri Liukko, Department of Social Research, University of Helsinki, FI
13. Professor Ruud ter Meulen, Director of the Centre for Ethics in Medicine, Bristol University
14. Dr Peter Mills, Assistant Director, Nuffield Council on Bioethics
15. Dr Christopher Nathan, School of Humanities and Social Sciences, University of Exeter
16. Professor Christopher Newdick, Professor of Health Law, University of Reading
17. Professor Anne Phillips, Professor of Political and Gender Theory, London School of Economics
18. Professor Barbara Prainsack, NCOB/NF/AHRC Solidarity Fellow and Reader in Medicine, Science & Society, Centre for Biomedicine & Society, Brunel University
19. Professor David Rhind, former Vice-Chancellor and President, City University London, Chairman of the Nuffield Foundation
20. Professor Klaus-Peter Rippe, ethik in diskurs, Zurich, CH
21. Hugh Whittall, Director of the Nuffield Council on Bioethics
22. Dr James Wilson, Lecturer in Philosophy and Health, University College London

23. Professor Tim Wilson, Professor of Forensic Sciences and Public Policy, Centre for Forensic Science, Northumbria University

24. Katharine Wright, Assistant Director, Nuffield Council on Bioethics

2nd workshop: 'Solidarity as a core value in contemporary bioethics: three case studies, 7 July 2011, NCoB, London

25. Sarah Bougourd, Communications Officer, Nuffield Council on Bioethics

26. Dr Alena Buyx, Assistant Director, Nuffield Council on Bioethics

27. Professor Ruth Chadwick, Distinguished Research Professor, School of English, Communication and Philosophy, University of Cardiff

28. Ho Chih-hsing, PhD student, London School of Economics

29. Professor Angus Clarke, Professor in Clinical Genetics, School of Medicine, Cardiff University

30. Dr Anthony Mark Cutter, Head of Innovation in Society, Lancashire Law School, University of Central Lancashire

31. Dr Angus Dawson, Senior lecturer in Ethics, Centre for Professional Ethics, Keele University

32. Dr Kathryn Ehrich, Research Fellow, Innovations Programme, NIHR King's Patient Safety & Service Quality Research Centre, King's College London

33. Professor Stephan Feuchtwang, Director of the Masters programme on China in Comparative Perspective, Department of Anthropology, London School of Economics

34. Dr Beth Greenhough, Lecturer in Geography, Queen Mary, University of London

35. Professor Ine van Hoyweghen, Assistant Professor, School for Public Health and Primary Care, Health, Ethics and Society Programme, Maastricht University, NL

36. Varsha Jagadesham, Research Officer, Nuffield Council on Bioethics

37. Catherine Joynson, Communications Manager, Nuffield Council on Bioethics

38. Dr Nadja Kanellopoulou, Researcher in Law, HeLEX - Centre for Health, Law and Emerging Technologies, Department of Public Health, University of Oxford

39. Dr Tim Lewens, Director of Studies in Philosophy, Senior Lecturer in History and philosophy of Science, University of Cambridge, Nuffield Council on Bioethics member

40. Professor Ruud ter Meulen, Director of the Centre for Ethics in Medicine, Bristol University

41. Dr Peter Mills, Assistant Director, Nuffield Council on Bioethics

42. Professor Terrie Moffit, Knut Schmidt Nielsen Professor, Departments of Psychology and Neuroscience, Psychiatry and Behavioral Sciences, and Institute for Genome Sciences and Policy, Duke University, US; and Professor of Social Behaviour and Development, Social, Genetic and Developmental Psychiatry Centre, King's College London

43. Professor Christopher Newdick, Professor of Health Law, University of Reading

44. Dr Jo Newstead, Head of International Business, Pandemic Flu, Department of Health

45. Dr Barbara Prainsack, NCOB/NF/AHRC Solidarity Fellow and Reader in Medicine, Science & Society, King's College London

46. Dr Andreas Reis, Department of Ethics, Equity, Trade and Human Rights, World Health Organization, WHO/IER/ETH

47. Professor Genevra Richardson, Professor of Law, King's College London

48. Dr Kadri Simm, Senior research fellow, University of Tartu, EE

49. Professor Marilyn Strathern, Former Mistress of Girton College Cambridge and William Wyse Professor of Social Anthropology, University of Cambridge

50. Hugh Whittall, Director of the Nuffield Council on Bioethics

51. Dr James Wilson, Lecturer in Philosophy and Health, University College London

52. Professor Jo Wolff, Professor of Philosophy, University College London, Nuffield Council on Bioethics member

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