

# 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 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 19<sup>th</sup> 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 19<sup>th</sup> 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 20<sup>th</sup> 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). Reciprocal 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 automatization 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.