PART I

Introduction

CAMBRIDGE

Cambridge University Press 978-1-108-48719-1 — Trust in Medicine Markus Wolfensberger , Anthony Wrigley Excerpt <u>More Information</u>

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Introduction

1.1 Everyday Use of 'Trust'

In her Presidential Address at the Scientific Session of the American Heart Association of 2004, entitled 'Rebuilding an Enduring Trust – A Global Mandate', Alice K. Jacobs said that "one of the most critical issues facing our profession today is the erosion of trust".¹

We do not doubt that Professor Jacobs got a thundering applause at the end of her address. After all, the decline of trust is something about which everyone might worry. Yet, it is likely that few in the auditorium would have been able to say what exactly they meant by 'trust', why they were worried about the decline of trust (apart from the fact that 'doctoring' had become more difficult lately), and what were the reasons for the alleged decline.

This statement may sound surprising, but it is not. It sounds surprising because we all use the word 'trust' and we all think we know what it is and when its use is appropriate. Yet closer inspection of the way people use 'trust' reveals that the term is often used in a range of different contexts. Here are just a few examples of 'what people trust'. They trust that the weather will be good at the weekend. They trust the brakes on their motorbike. They trust that their car will keep going for another year. They trust that their partner will be faithful. Some people even say that they trust in homeopathy.² What these examples illustrate is that this everyday usage or 'folk' understanding of 'trust' is very broad. As we will discuss later, it would probably be more appropriate when considering issues of clarity and accuracy to replace many instances of 'trust' with some other term. To continue with the examples just mentioned as illustration, it would be more appropriate to say that we hope that the weather will be good; that we rely on the brakes; that we are confident that the car will keep going; that some people believe in homeopathy. In these

² Of course, people also trust in God. We will leave this aside, because it belongs to the discourse of religion and faith – two topics that are outside the scope of this book.

¹ Jacobs 2005, p. 3494.

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instances, the use of the term 'trust' should ideally be limited only to the case of the faithfulness of our partners. As long as 'trust' is used so imprecisely and in so many different ways, discussion about the meaning, the decline, and the value of trust must border on the futile. Yet, not only the folk understanding but even the definitions of 'trust' we find in the literature are, on the whole, rather vague and (as we will discuss in Chapter 3) neither sufficient to explain the decline of trust. It therefore follows that our first and foremost need is an expedient definition of 'trust'. To present such a definition is one of our goals. To avoid any misunderstanding, we do not aspire to present a definition of 'trust' in general but only a definition of 'trust in medicine' or even more particularly of 'trust in physicians' (and other healthcare professionals).³

1.2 Two Model Case Histories

Throughout this book, we will try not to argue in the void but to illustrate our arguments with examples (whenever possible from the field of medicine). To set the stage for what is to follow, let us start by presenting *two short model case histories.*⁴ Their purpose is to show why we believe that trust has declined and to point to some of the consequences of this decline. The beginning is common to both histories: one day a woman notices a small lump in front of her ear. Since it is painless, she is not overly worried, but when it does not go away after a few months, she consults a physician.

1.2.1 First Case History

After listening to her history, asking a few pertinent questions, and palpating the lump, the doctor tells the patient that this is almost certainly a so-called pleomorphic adenoma of the preauricular salivary gland (the parotid gland).⁵ He⁶ tells her that this is a benign tumour but that he

³ Although, given the particular expertise of the authors, our primary focus is clearly on trust in the patient–physician relationship, the concept of trust we are offering here we take to be equally applicable to other healthcare professions.

 ⁴ The two case histories are modelled on real cases from the practice of M.W. but are slightly idealised for didactic purposes.

⁵ Pleomorphic adenomas are the most common tumours of the parotid gland.

⁶ Whenever possible, we have attempted to establish gender balance in our examples through regular use of the female pronoun 'she' or 'her'. However, in cases where we

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would nevertheless recommend removing it. After briefly reflecting upon the diagnosis and recommendation, and after consulting with her family, the patient agrees and goes ahead with the recommended surgery.

1.2.2 Second Case History

After listening to her history, asking a few pertinent questions, and briefly examining the patient, the doctor performs an ultrasound exam of the lump and recommends taking a fine-needle aspiration biopsy. After he has reassured the patient that this is a harmless and almost painless procedure, she agrees to it. The aspirate is sent to a pathologist and, a few days later, the patient is told that the cytology (i.e. the result of the needle biopsy) is compatible⁷ with a pleomorphic adenoma of the parotid salivary gland. She is informed that (in all likelihood) this is a benign tumour but that, since no biopsy can ever completely rule out a malignant tumour (because a few percent of all pleomorphic adenomas have a malignant component that may have been missed by the aspiration biopsy) and since about 5 per cent of all pleomorphic adenomas will eventually turn malignant if left in place for ten or more years, he would advise her to have the tumour removed. Chances are that ('just to make sure') the doctor will also send her for a computerised tomography (CT) and/or a magnetic resonance imaging (MRI) exam. Of course, he tells her all about the side effects and potential risks of the surgery. Finally, the conscientious physician tells her that there is no alternative treatment option and that even after properly performed surgery there is a 5 per cent risk of a later tumour recurrence. Yet, although this is comprehensive information, based on the 'best available evidence', the patient will look for further information: at least she will 'surf the Internet'. Perhaps, she will see another physician to get a 'second opinion'. She also asks the surgeon whether 'he has ever seen such a tumour' and 'whether he has performed the proposed operation before'. If she is brash, she may even ask whether he would also recommend the surgery if she did not have private insurance coverage. Perhaps, she will also consult a practitioner of some type of 'alternative medicine' before she eventually decides to go ahead with the operation.

have not done so, the reader is solicited to read the male form in the sense of a generic pronoun implying both genders equally.

⁷ 'Compatible with' is common medical usage and is not to be confused with 'proves that'.

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At first glance, the two stories may appear as the short and the long version of the same story, which, indeed, they almost are. The significant, if unstated, difference is that whereas the first is from the 1970s, the second is from today. Furthermore, there are two other major differences between the stories, which can be gleaned from the description: the first refers to the amount of workup (i.e. the number of tests and exams); the second refers to the interaction between the patient and the physician (i.e. the patient–physician relationship). These differences are key to helping us understand trust.

With regard to the increased amount of workup, one might argue (1) that it reflects 'progress' and the increasing sophistication of medicine. Of course, this is true, but it is only part of the explanation. Not all of these exams are truly indicated,⁸ and this amount of workup is definitely not cost-effective. If you consider that in this case the pretest probability of the lesion being a benign pleomorphic adenoma is above 90 per cent, it is questionable whether, in addition, fine-needle aspiration biopsy, CT, and MRT will add new information that would significantly change the treatment recommendation.⁹ Besides, one could argue (2) that the changes in the patient-physician interaction only reflect the newer, more modern self-perceptions patients have, as seen through its focus on patient autonomy, the patients' desire of taking control and participating in decisionmaking, and finally their increased access to information. Yet again, this is only part of the explanation. What we want to claim is that both changes are, to a considerable part, caused by the decrease of patients' trust in physicians.

1.3 A Brief Explanation of Changing Views on Trust

A scrutiny of the second history reveals that it abounds with clues (some subtle, some not so subtle) pointing to the patient's *mis*trust.¹⁰ Whereas the patient in the first history takes the physician's trustworthiness for granted (and therefore trusts him without further ado), the patient in

⁸ 'Indicated' is again a standard medical term, meaning there is good evidence that an exam

gives *new* and *essential* information. Unfortunately, the term is often used far too liberally. ⁹ We will argue in the next section that the addition of ever more tests and exams is not so much justified by their diagnostic value but by the fact that many physicians practice what is commonly called 'defensive medicine' out of fear of litigation.

¹⁰ '*Mis*trust' is one of a range of technical terms that form part of our account of the concept of trust. We will define this and other related terms in detail in Section 6.1.

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the second story appears to have serious qualms about the physician's trustworthiness. Her question 'have you ever seen such a tumour before?' implies 'can I trust your diagnosis?', and her question 'have you performed this operation before?' means 'can I trust your surgical skills?' For the patient these questions are a means of assessing the physician's competence. The fact that many, if not most, patients today consult the Internet after the consultation also points in the same direction: it serves to assess the physician's epistemic trustworthiness, which today's patients no longer take for granted. The question 'would you recommend surgery if I did not have private insurance coverage?' implicitly expresses doubts about the physician's integrity. From the reaction to this and similar questions, the patient tries to gauge the doctor's honesty, to find out whether he indeed has her, rather than his own, interest foremost. In other words, she tries to assess the physician's commitment to her. Although the patient may not perceive (let alone intend) these questions as expressions of mistrust, the physician may perceive them as questioning his professional competence and integrity (in short, of his trustworthiness) and, hence, as a sign of mistrust.

This mistrust not only explains the changes in the patient-physician relationship that have occurred over the past decades. It also explains the ever-increasing number of diagnostic tests ordered by physicians, because the physicians (fearing that a mistrusting patient is more likely to be dissatisfied, or even litigious) react to the perceived mistrust by practising what is called 'defensive medicine',¹¹ i.e. they order more tests than they really think necessary 'to hedge their bets', to be on the safe side if ever they should be called to account for their actions. Nickel calls this 'positive defensive medicine' (or 'assurance behaviour'), which he defines as behaviour that "involves supplying additional services of marginal or no medical value with the aim of reducing adverse outcomes, deterring patients from filing malpractice claims, or persuading the legal system that the standard of care is met".¹² He then goes on to differentiate this type of defensive medicine from what he calls 'negative defensive medicine' or 'avoidance behaviour', which refers to situations where physicians, for example, refuse to treat high-risk patients.¹³

¹² Nickel 2009, p. 358.

¹¹ Berlin 2017.

¹³ In fact, defensive medicine need not always be caused by mistrust. If a patient trusts (expects) a doctor to prescribe an antibiotic for the common cold, then the doctor's 'failure' to do so can be resented as a breach of trust. Knowing the cost of such 'failure',

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The comparison of our two typical case histories (one from the 1970s and one from today) underpins our claim that trust has declined over the past forty years or so. We have also learnt from the two stories that trustworthiness and, hence, trust refer to both competence and patient-oriented commitment of the physician. Yet, there is more we can learn about trust from the two stories. The simple fact that patients feel compelled to ask these questions points to two other important features of the patient-physician relationship and, hence, of trust: *uncertainty* and *risk*. The patient is aware that she can never be sure about the physician's trustworthiness and that therefore to trust always means to run a risk. By asking such questions she tries to reduce the uncertainty and, hence, the risk. Finally, the two histories show that the reasons for which patients' trust (i.e. how they justify the risk of trusting) have changed over the years. Whereas in the past most patients trusted doctors simply qua doctors, most of today's patients trust a doctor only if they have good reason to assume that the physician merits their trust.

As such, the two histories not only show that trust has declined over the past forty years or so. They also tell us that how the patient perceives both competence and the patient-oriented commitment of the physician determines the patient's trust; that uncertainty and risk are important features of 'trust'; and, finally, that the way patients justify taking the risk of trusting has changed. Although many people share our concern about the erosion of trust and its consequences,¹⁴ not everyone agrees that the decline of trust is real rather than imagined. Since the claim that trust has declined is a factual claim, it should be possible, at least in theory, to prove or refute it empirically. In Chapter 2, we will therefore present a brief summary of the available empirical literature on trust. Admittedly, the evidence for the decline of trust may be challenged; yet this applies to most evidence in the social sciences.¹⁵

doctors may attempt to live up to patients' trust even when this is not medically appropriate. In other words, 'trust can be bad, not because moral expectations are disappointed, but rather because they are *met*'. Nickel 2009, p. 359.

¹⁴ See, e.g. Shore 2007.

¹⁵ At the very least, the empirical evidence taken from this literature provides a reasonable foundation for supporting our claim about the decline of trust, and it is not the purpose of this book to engage in empirical and sociological investigations of our own. Although the authors would, of course, welcome further work in this area by social scientists interested

1.4 OUTLINE AND STRUCTURE

1.4 Outline and Structure

As we mentioned at the very outset of the book, our approach is one of analytical philosophy and bioethics. This methodological approach is one that primarily critically assesses argument and seeks to provide a clear and rigorous analysis of concepts. As such, the structure of this book reflects this approach, with an emphasis on definitions and argument analysis. Accordingly, we are interested not simply in proposing a suitable definition of trust in the medical context, although this is certainly a major aim of the book. We are interested in exploring the reasons why we need to account for trust in this way. Partly, this is the product of subjecting various possible definitions of trust to a detailed analysis to see if they are 'fit for purpose'. The other aspect of this, however, is that we want to explain why we need trust, why the loss of trust is a bad thing, and how a good account of what trust is can help us to suggest ways in which we might go about restoring the evident loss of trust that has occurred in the field of medicine.

Therefore, rather than simply going through one potential definition of trust after another, the book is structured to take on different issues that surround the question of trust in medicine.

Chapter 2 begins this process by looking at what empirical evidence we have for thinking there has been a decline in trust in the context of medicine over recent years.

Chapters 3–7 address the fundamental questions of our definition of 'trust'. We start with a critical analysis of existing definitions (Chapter 3). Next, we propose a new type of definition (Chapter 4) and then use this type of definition to define 'trust' (Chapter 5). Since 'trust' is often used interchangeably with concepts such as 'confidence', 'reliance', 'belief-in', and 'hope', we will analyse how our definition of 'trust' can separate and distinguish these concepts, both from itself and from each other (Chapter 6). Finally, we will end this part by demonstrating that our definition of 'trust' can accommodate different situations (Chapter 7).

Chapters 8 and 9 consider the justification of trust. Chapter 8 will be devoted to the justification of epistemic trust and Chapter 9 to the justification of patients' trust in physicians.

in the topic, the conceptual analysis of trust that we offer can still be understood without this contextual framework.

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Chapters 10 and 11 focus on aspects of the significance of trust, first from an instrumental (Chapter 10) and then from a moral standpoint (Chapter 11).

Chapter 12 seeks to explore some of the reasons for the decline of trust.

Chapter 13, finally, will round off our analysis of trust with a few thoughts on whether and how (at least some) trust can be regained by individual physicians as well as by healthcare institutions.