

Alone we can do so little, together we can do so much

A recommendation report from Aurora Healthcare Communications on collaboration in the healthcare system



Executive summary:

Current media narratives often focus on sensationalist headlines regarding financial payments between pharmaceutical companies and healthcare professionals. Financial conflicts of interest are rightly documented in an increasingly transparent fashion but a move towards greater documentation of non-financial and ideological conflicts of interest from all participants, including 'commentators' is overdue.

The increasing complexity of the healthcare and scientific landscape means that collaborative working between all stakeholders in health is more important than ever. Greater collaboration and shared learning between all parties, including industry, can drive health systems to be more efficient, provide greater focus on prevention of ill health and help ensure patients gain access to innovation when they need it.

Through this report we discuss some of the evidence underpinning the drive to work together, as well as examples of collaborative pieces of work and what we can learn from them. These examples reflect our experience, showing that despite the negative emphasis of what may be widely reported, there are many examples of successful public-private collaborations in healthcare. Instead of driving to fracture the healthcare system further, we should be seeking to learn from what has worked well and replicate this as standard.

The problems facing us in health are becoming too big to tackle alone, we must find a way through them together.

Aurora believes doing well by doing good through collaboration has tremendous impact and we reveal:



The common, positive trends we have seen while immersing ourselves in this topic



The practical and mindset changes needed to move to a more collaborative future, which we call The Age of Enlightened Self-Interest



What we can all do to improve the health discourse across the country

Chapter 1

Collaboration, transparency and the importance of getting it right



Introduction

In January 2018, the world-renowned Alzheimer's researcher, Professor Bart De Strooper wrote an article in the Guardian newspaper, which discussed the news that the pharmaceutical company Pfizer was ending its neuroscience discovery programmes. The article set out the importance of the pharmaceutical industry in ensuring the development and delivery of life changing and lifesaving medical treatments. He said "Pharmaceutical companies are absolutely crucial in our war against Alzheimer's and other dementias, and their input, financial muscle and insight hold the key to better treatments and prevention."1 In this article, we see a logical discussion of the importance of private investment into drug development and the role industry can play.

Conversely, we are faced with headlines such as "Doctors involved in assessing which drugs should be prescribed to NHS patients are receiving up to £100,000 per year from pharmaceutical companies."² "Scandal of experts who rule on NHS statins but get paid by drugs firms."³ These headlines claim to demonstrate the overly close relationship between the pharmaceutical industry and clinicians. As a result of this complex and confusing narrative played out through the media, it reads as though we need collaboration with industry on the one hand, but don't want it on the other hand. We need to ask ourselves what the implications of this are.

The close working between different parties in healthcare has been a source of tension for some time. As Professor Gillian Leng, Deputy Chief Executive at the National Institute for Health and Care Excellence (NICE) stated:

[We are] caught between the critics who say NICE is being 'ridiculous' for not listening to the experts, and those that say we are being overly influenced by those with a vested interest..."⁴

The quote from Professor Leng demonstrates the difficult position that all in healthcare face. How do we encourage close working with industry to ensure clinical staff understand new innovations and are confident to use them while safeguarding against undue influence?

Let's be clear, there will never be an easy answer to this. Like so many issues we face, it is not, and never will be, black and white, despite what sensationalist headlines may want us to believe. While many would like to see no interaction between any commercial organisation and any healthcare professional or body, complete lack of interaction does not feel like any way to optimise healthcare. Surely with the resource and knowledge contained within the four walls of a commercial organisation they have a lot to offer?

In 2015, Aurora developed a research paper called *Creating opportunities for improving patients' access to medicines*, which sought to examine the UK challenge of medicines access through the lens of 'systems thinking'.⁵ Within this paper we discussed seven key dependencies, which we believe can positively impact the uptake and flow of medicines in our health system. One of those dependencies was Collaboration and Governance. Our findings on the access barriers within this dependency were that:

Actions taken, without the consultation of other parties, are more likely to result in conflict, duplication and failed endeavours. This creates delays and barriers to access."⁵

In essence, working closely together rather than further apart gives us a greater chance of ensuring access to innovation.

However, while collaboration can without doubt be a positive influence in healthcare, unrestricted, unregistered contact between a pharmaceutical company and a healthcare professional is not feasible nor advisable. This would, without doubt lead to significant and severe conflicts of interest. It is important to remember, that the current system of industry working with healthcare professionals is far from the 'wild west' it is sometimes portrayed to be. The Association of the British Pharmaceutical Industry (ABPI) is the body who represent the views of biopharmaceutical companies and produces its own Code of Practice. The ABPI Code of Practice is administered by The Prescription Medicines Code of Practice Authority (PMCPA) at arm's length of the ABPI itself.⁶ This Code of Practice contains several clauses with regard to collaboration, including working with healthcare professionals and patient groups/charities. This self-regulated approach ensures companies can be held to account for overstepping the mark, the results of this can be seen in the public record of code breaches⁷

The ABPI Code of Practice for the Pharmaceutical Industry

The Code sets standards for the promotion of medicines to health professionals and other relevant decision makers in the UK. It includes requirements for the provision of information to patients and the public and relationships with patient groups. The Code also applies to a number of areas that are non-promotional.

While it should be noted that this paper will not discuss every potential contact between commercial organisations and healthcare professionals, there are definite ethical considerations and evidence we need to discuss.

The intricate world in which we live

If the world we live in now is complex, things are going to get significantly more so in the coming decades. The much discussed promise of regenerative medicine appears to be rapidly

advancing towards us. The use of regenerative medicine promises to not only treat an illness but has the potential to help return our bodies to normal function. Development of these treatments is a vastly complex and precise scientific and logistical challenge, and presents unique difficulties which need to be addressed by a multidisciplinary team.

To emphasise this point, at a recent Westminster Health Forum meeting: The future for regenerative medicine, advanced therapies and stem cell research, Prof. Antonio Pagliuca, National Clinical Lead for Regenerative Medicine, NHS England, commented

This is a very complex process, gone are the days I rang up the supplier who sent me the drug, it was in a package and I gave it to the patient, it came through pharmacy and waved bye-bye to them and they went home and took it and hopefully there weren't too many toxicities. This is a product where we are intertwined at the hip with the industry partner."⁸

Alongside the complex creation and administration of these treatments, the way we assess the impact of them needs to be discussed, as The House of Lords Science and Technology Committee acknowledged in their 2013 report:

Many of the cost-savings that regenerative medicine products might offer would be outside the healthcare budget and that current methods of assessment would not take these into account."9

Alongside these cutting-edge medical advances, we are living longer and as such have a greater chance of becoming clinically complex patients. As pointed out in 2010 by Steinman and Hanlon,

Multiple medication use is common in older adults and may ameliorate symptoms, improve and extend quality of life, and occasionally cure disease. Unfortunately, multiple medication use is also a major risk

factor for prescribing and adherence problems, adverse drug events, and other adverse health outcomes."¹⁰

Many of us will have faced these issues in our own families, and have an ingrained understanding about the need for collaboration in this difficult and stressful situation.

These are two examples of how the healthcare landscape is increasing in complexity and will require a more efficient and collaborative way of working to tackle these problems. It is vital that all stakeholders are involved in this. The emphasis on collaboration with patients has been seen throughout the last decade in healthcare, from the NHS report, *"No decision about me, without me"*¹¹ to the patient partnership strategy and appointment of a patient editor at the *BMJ*.¹²

The pharmaceutical industry has also recognised the importance of collaborating with patients across the lifecycle of products.¹³ While, there have been good examples of collaboration, a reticent approach to working with patients can often be found in the pharmaceutical industry. A 2016 paper (funded by Novartis Pharmaceuticals), which interviewed senior employees in the pharmaceutical industry found that while the benefits of aligning research to the needs of patients was clear, many barriers and concerns were identified.¹⁴ These barriers and concerns. will in all likelihood, be a significant cause of the reported "varied approach to the adoption and implementation of patient-centric initiatives [seen in the pharmaceutical industry]."15

While an increased focus on collaboration with patients is largely welcomed, the same cannot be said of industry working with healthcare professionals. A recent publication reviewed the global literature regarding interactions between physicians and the pharmaceutical industry, in relation to prescribing habits. The publication found that "pharmaceutical industry and pharmaceutical sales representative interactions compromise the objectivity of the physicians."¹⁶ Their conclusions, alongside

others before them, were based on the fact that prescribing habits of clinicians were altered towards the company product after interaction. It would be wrong to infer this is *always* a bad thing. Healthcare professionals are intelligent individuals, who have the experience of a disease to assess if the data presented create a compelling argument for use. They are also extremely busy and under significant pressure so need effective education and information about innovative medicines, and if done correctly, transparently and to high standards, why can the pharmaceutical industry not play a role in this? Done well, the interaction might be best for the patient after all.

Through collaborative working with healthcare professionals, Aurora has found that medical education meetings, for example, lead to feedback from attendees about a willingness to use a product based on 'increased confidence' or 'greater understanding of the mode of action'. In essence, these interactions with the pharmaceutical industry can provide valuable education and training for them that, despite best efforts, they may not get elsewhere. This work is not statistically manipulated or disingenuously edited, it is factual and fair, balanced and accurate. If it is not, then the company gets publicly investigated and admonished.

The complexity of how and why healthcare professionals prescribe new drugs has been documented in the literature.¹⁷⁻²⁰ Within this, confidence has been identified as a key factor in prescribing decisions.²¹ Healthcare professionals are not robots, nor are they perfect, they are human and must make constant decisions at pace every single day. The link between confidence and prescribing is therefore not a surprise. As such, we should pose the following question: If undertaken to rigorously high standards, can pharmaceutical interaction with healthcare professionals lead to changes in prescribing which benefit both the healthcare system and patients?

The inference that any and all interaction between healthcare professionals and the pharmaceutical industry leads to a negatively altered behaviour is not only false, but may also lead us down a path whereby the healthcare system is missing out on important knowledge transfer. For example, if interactions between healthcare professionals and industry are removed, there is potential for healthcare professionals more broadly to miss out on real world evidence and case studies, which may give them confidence or knowledge to prescribe a treatment correctly leading to improved outcomes for their patients, ultimately improving and saving lives.

Another dimension of the conflict debate

Many people will state that a financial payment from a company (in any field) to an individual is an automatic conflict of interest. However, looking at alternatives, are we asking people to work for free, or to work for the company as an expert full time and leave their position in the NHS (and remove themselves from clinical practice), or academia, or never collaborate with anyone with any industry involvement? We must be able to reach a happy middle ground where we document and discuss potential conflicts, while not assuming that everything is an automatic conflict, which should disbar someone from an opinion.

There is also another side to this argument which seldom sees the light of day. Many detractors or campaigners 'against' industry (whatever industry that may be) have their own potential conflicts of interest. They may have book deals and high profile media appearances, which are based on their position in this argument. Is this not a conflict of interest against their independence in this argument? For example, if new evidence or data are published and you have one or several books published which state a particular point of view, are you truly able to give an honest independent assessment of this, even if it goes against what you have previously written, and if it may affect sales of your book? The most striking examples of this can be seen in the world of nutrition, where doctors, nutritionists and others often criticise the food industry, but then are quick to follow up with their own diet book and media tour. If they have sales targets for their book, and their position is explicitly anti-industry, how do we know that it is not simply because they want to sell their own book? Or to appear on television again?

This is not to denigrate or criticise one person or one moral position, it is simply to raise awareness of the breadth of potential conflicts that we are all entangled with. The importance of considering this is demonstrated by the nonfinancial or even ideological conflicts of interest that are now rightly considered alongside financial conflict of interests, as demonstrated by the conflict of interest policy of *Nature*.²²

The importance of considering all biases, from all audiences is further demonstrated by the excellent and genuinely informative Catalogue of Bias (https://catalogofbias.org/).²³

Non-financial competing interests from Nature:²²

Non-financial competing interests can take different forms, including personal or professional relations with organizations and individuals. We would encourage authors and referees to declare any unpaid roles or relationships that might have a bearing on the publication process. Examples of non-financial competing interests include (but are not limited to):

- Unpaid membership in a government or non-governmental organization
- Unpaid membership in an advocacy or lobbying organization
- Unpaid advisory position in a commercial organization
- Writing or consulting for an educational company
- Acting as an expert witness

The cost and value of conflict

Fundamentally, many arguments will often come down to cost, which is understandable. As the evidence above stated, healthcare professional interactions with industry can be correlated to rises in prescriptions of branded medicines, which in turn leads to increased cost to the health system. As more high cost genetic, regenerative and biologic medicines get approved, it is understandable that this is of concern to those who care deeply about the health system.

It is thought that the NHS currently spends approximately 15 per cent of its total budget on medicines (excluding discounts) and that seventy per cent of the £120 billion annual NHS budget is for conditions that might have been preventable.^{24,25} Similarly, inefficiencies and waste within health systems have long been the subject of debate, and a 2017 report by the Organisation for Economic Co-operation and Development (OECD) found that "one in ten patients is adversely affected during treatment by preventable errors, and more than 10% of hospital expenditure is allocated to correcting such harm".²⁶ More specifically to the NHS, a review by Lord Carter in 2016 found unwarranted variation in English non-specialist acute hospitals worth £5bn in efficiency opportunity.27

While cost of medicine is an important conversation to have, are conversations such as this taking away from conversations which could contribute more to society? Compared to the 'cost' of a medicine, there seems to be little conversation about the 'value' of medicines. What value to society is a treatment that prevents someone from going blind, what can that person achieve in life they could not have done before? How much less of the healthcare resource are they now using?

The pharmaceutical industry of course has to be cognisant of affordability, but there will always be technological advances on the horizon which will be high cost. Alongside

reasonable pricing and innovative funding models, we as society need to discuss how we are going to ensure people who need them, get access to these innovations. A focus on prevention, encouraging all of us to stay in 'good health' and away from the healthcare system as much as possible is surely a key aspect of this conversation. Less spend on preventable illness and inefficiencies can ensure a greater spend on non-preventable illness. This focus on prevention was echoed by Duncan Selbie, Chief Executive of Public Health England, in his Christmas 2017 message.²⁸

Alongside the focus on patient empowerment, an equal focus on public empowerment to encourage a seismic shift in approach to preventative health needs to take place.

Collaboration is crucial to the future of the nation's health, the sharing of education, maximising the efficiency of health systems and allowing patients to gain access to innovations. The advent of greater transparency around healthcare professional interactions and the recognition of the importance of patients is a demonstration of the shift in focus of collaboration in healthcare.

Speaking at J.P. Morgan's 36th Annual Healthcare Conference in January 2018, Bill Gates succinctly summarised the importance of collaboration.

"We all share the goal of improving the health and well-being of people globally. Imagine what's possible if we work together".²⁹

Aurora could not agree more.

Chapter 2

Getting it right: Examples of successful collaboration



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Why we collaborate:

We have known for centuries that one person cannot possibly stand alone when it comes to driving knowledge forward. As far back as 1675, Isaac Newton recognised that each of us needs to build on the work done before us when he wrote



Since then, as the world has become more complex, the burden of knowledge has grown ever greater. The concept of the "burden of knowledge" is an interesting one. Essentially, as the totality of knowledge increases in the world, what we as individuals can know is becoming relatively smaller, so we need greater collaboration to solve the most complex problems.³¹ In fact, the recent round of Nobel Prize awards, have been criticised by both academia and the media for failing to reflect the collaborative reality of modern science by awarding only named individuals and thereby rewarding "an outdated version of science."32 The President of the Royal Society, Venkatraman Ramakrishnan (himself a winner of the Nobel Prize), has criticised the prize as "increasingly becoming a lottery."³³ Similarly, The Astronomer Royal, Sir Martin Rees commented

The fact that the Nobel committee refuses to make group awards is causing them increasingly frequent problems – and giving a misleading and unfair impression of how a lot of science is actually done."³⁴

This speaks to a point we raised in the first chapter. As medicines and the health system become more complex, we need to put in place a pan-industry approach to ensuring patients get access to innovation. Ultimately all stakeholders (industry, NHS, healthcare professionals, patients, public etc.) bring a different perspective and hold a different set of expertise, which can and should be utilised so that we can optimise the future of the health system.

Collaboration has been shown to be variable between different scientific disciplines, though

interdisciplinary working is slowly increasing. Interestingly, it was found that having female scientists in a team, research experience, and prior work experience in private firms or governmental organisations are all factors that increase the propensity of interdisciplinary collaborations in science.^{35,36} Within medicine, the importance of interdisciplinary collaboration has been noted and positive effects on patient outcomes have been demonstrated.37 Similarly, within the pharmaceutical industry, the importance of collaboration (in particular in research and development) has been regularly discussed since the 1980s.³⁸ What is lacking however, is a focus on collaborative knowledge sharing and problem solving across both public and private sectors to ensure patients get access to innovation.

Doing it right. Examples of collaborative working:

There are various commentators who are opposed to collaborative working who may look upon patient access schemes (innovative pricing agreements designed to improve cost effectiveness and facilitate patient access to specific drugs or other technologies)³⁹ as the only element of collaboration needed between pharmaceutical companies and the wider health system. However, if we impede collaborative working, we are missing out on innovative and effective ways to improve the health system for us all. The following examples of successful collaboration, which are reported in the public domain, give a good overview of what can be achieved. The results contained in the following case studies can be attributed to collaborative working. It is worth bearing in mind, the impact of non-collaboration in these cases may have led to many more years of work to find the answer, or in fact, never solving the problem at all



The Salford Lung Study⁴⁰⁻⁴²

The Salford Lung Study (SLS) comprised two phase 3 real-world pragmatic randomised trials evaluating once-daily inhaled fluticasone furoate (FF) combined with vilanterol (VI) in patients with COPD or asthma in and around the city of Salford, UK. It was a randomised controlled trial which included a broad and inclusive population of patients in an everyday clinical practice setting, embracing a novel approach to clinical trial design. SLS included those patients who would often be excluded from a traditional randomised trial, for example individuals also being treated for other chronic diseases. This approach is important because it is more realistic of everyday practice and is therefore representative of a much wider patient population. The data provided by SLS complemented the existing data provided by the conventional randomised controlled trial.

The SLS was intended to enable healthcare professionals and decision makers to more fully assess the potential value of FF/VI by providing data collected in a normal clinical practice setting, which is representative of how healthcare professionals and patients may use the medicine in everyday life. It was made possible through a unique collaboration between GSK, NorthWest EHealth (NWEH), The University of Manchester, Salford Royal NHS Foundation Trust, University Hospital of South Manchester (UHSM), NHS Salford and GPs and community pharmacists in Salford, Trafford and South Manchester. The study involved over 4,200 consenting patients, supported by 80 GP practices and 130 pharmacies in Salford and the surrounding Greater Manchester area. Results demonstrated a statistically significant 8.4% reduction in COPD exacerbations when compared to usual care and clinically meaningful improvement in overall asthma control. Commenting on the study, Prof. Martin Gibson, Chief Executive of NWEH said

This is not about Big Data, this is about understanding the way patients interact with medications in their everyday lives. Our unique technology supports understanding of NHS data to bring the right drugs to market quicker, whilst providing timely and accurate information on safety and cost for payers and patients alike."



Effective Performance Insight for the Future (ePIFFany)⁴³⁻⁴⁴

ePIFFany was a joint funded project between Health Education England, NHS Midlands and East, University Hospitals of Leicester NHS Trust and Pfizer. The collaborators worked together to create a multifaceted educational approach, with four teaching components (including real clinician and patient feedback), which focused on improving the prescribing performance of junior doctors to increase patient safety and reduce human error. University Hospitals of Leicester reported that ePIFFany resulted in a 50% reduction in prescribing errors with a potential cost avoided of £308,928 and a total of 489 bed days saved. ePIFFany also led to an extra 13.3 Quality Adjusted Life Years (QALY) improvement in health for patients as a result of avoiding the harm of medications at a cost of £2,739.77 per QALY. When additionally implemented at Boston Hospital in Lincolnshire, prescribing errors were reduced by 60%.



The Innovative Medicines Initiative (IMI)⁴⁵

IMI is funded by the European Union (represented by the European Commission) and the European pharmaceutical industry (represented by The European Federation of Pharmaceutical Industries and Associations [EFPIA]). IMI funding supports participation in its projects by universities, research organisations, patient organisations, small and medium-sized enterprises (SMEs), and mid-sized companies. It has supported over 7,000 project outputs, by 2,171 participants in 101 projects. There have been many successful collaborative projects to come out of IMI, including:

• Using health records to help clinical research. This project sought to enable scientists to search electronic medical records for suitable patients within a growing network of European hospitals, without seeing any personal information about them. It is predicted that using the platform to speed up trial planning and recruitment could reduce the time taken to set up and run a clinical trial by three to six months, thereby improving the speed of potential drug development.⁴⁶

What we did was to research and develop a scalable solution for using electronic health records across many hospitals in Europe without jeopardising or violating data security. Europe has the strictest data protection laws in the world, so if we could solve this problem here then we could solve it anywhere... It's not just about the technology – it's about the relationships and the interactions between people and organisations that lie at the heart of it." said project coordinator Mats Sundgren from pharmaceutical company AstraZeneca.

• Development of novel ways to predict safety and side effects of new candidate medicines. eTOX project partners developed innovative strategies and novel software tools to better predict the safety and side effects of new candidate medicines for patients.

The database contains information about 2,000 drugs and drug candidates that were investigated in pharmaceutical companies. The studies done on these compounds amount to about nine million data points about the toxicology of those compounds. This is a wealth of data which can be used to develop predictive models" commented Academic coordinator Ferran Sanz of Institut Hospital del Mar d'Investigacions Mèdiques, France. Francois Pognan of Novartis added

Just the fact we were able to share all this data between companies, who are normally competitors, is a big achievement. We found a way to share the unsharable."⁴⁷



Rheumatoid Arthritis MRC–ABPI (RA-MAP) Consortium⁴⁸

The RA-MAP Consortium is a group of over 140 individuals from 21 academic and industry organisations who collaborate on stratified medicine and creating genomic solutions for rheumatoid arthritis. The consortium was founded following a successful funding application to UK Medical Research Council (MRC) and the Association of the British Pharmaceutical Industry (ABPI). A key element in the collaborative approach to working was the close relationship between the funding body and the researchers. Several challenges were identified and solved throughout the collaboration, from data ownership and project management, to staff turnover and publication planning. Data have been submitted for publication and future work will concentrate on integrating the stratification tools into clinical practice. The RA-MAP consortium has joined forces with other consortia to better understand immune-mediated inflammatory diseases.



Greater Manchester and Pharmaceutical Industry Partnership Group⁴⁹⁻⁵²

In 2017, a first-of-its kind partnership was formed in the UK between the Greater Manchester Health and Social Care Partnership and the pharmaceutical industry. The aim of this was to improve the safety of medicines and utilise the NHS' data and information capabilities to discover, develop and ultimately deliver new medicines and treatments. Alongside this, they aim to explore more effective ways of paying for medicine based on patient outcomes. A further collaboration in Manchester was put in place in 2018 which will seek to improve dementia care, specifically looking at development of new medications and ensuring that existing medicines are prescribed correctly, as well as how new technologies and digital innovations can improve quality of life. While these are in the early stages, it is exciting to see these broad partnerships in place.

Our understanding of the science behind dementia is evolving, pointing to new ways of detecting and treating dementia that might be able to change the course of the disease in the future. We are proud to be partnering with Health Innovation Manchester and the Greater Manchester network to maximise the impact of current and future medicines on the lives of patients and their families," said Harry Brady, chair of the Dementia Industry Group and director, Policy and Communications, for pharmaceutical company MSD.

Joint Working^{53,54}

Aside from these examples, it should be noted that the Department of Health, NHS and ABPI have developed a support package for the NHS and industry on successful Joint Working, which includes a number of recommendations looking at strengthening the relationship between the NHS, ABPI and the pharmaceutical industry. There are also successful case studies, similar to above, which further demonstrate the positive outcomes of collaboration, and these can be found **here**. In addition, the ABPI and National Voices (a coalition of health and social care charities) jointly published guidance on collaboration between pharmaceutical companies and charities.

Successful case studies across a variety of NHS focused categories, including pharmaceutical partnership can also be found on in the HSJ Partnership awards, which will run for the second time in March 2019. A review of 2018 case studies and award winners can be found **here.**

Finding the common ground in successful collaborations

These above examples represent some interesting case studies of successful collaboration and demonstrate the breadth of collaboration from early stage research through to population challenges. However, it is not just the technical and knowledge crossover which leads to successful collaboration. Indeed, these may be of far lesser importance. In an interesting study, when investigating the skill set of successful collaborators, O'Leary *et al.*, found members of the US Senior Executive Service more frequently mentioned individual attributes and interpersonal skills rather than strategic leadership or technical expertise.⁵⁵

When reviewing the examples above, several key traits that appear to be present, are respect, persistence and open-mindedness. Drawing on Aurora's extensive experience with successful collaborations, these traits resonate strongly. Regardless of the disease area or specific type of project there are things that have consistently stood out to us through our work, in which respect, persistence and open-mindedness play a key role. At Aurora, we have developed three key principles, which are helpful to have in mind, when embarking and navigating collaborative working.

Aurora's top three principles for successful collaboration:

1. Have a common, clear anchor

First and foremost, the most successful collaborations that we have worked on have all begun with the end goal of genuinely improving specific patient outcomes. For example, this make take the form of access to a new treatment for an underserved patient population or providing a support service that will enable greater patient independence and reduce nurse time. This focus gave an anchor for the project and clear focus for all involved. While the dayto-day process of getting to your end goal may be difficult, having that anchor point allows a common reference point for decision making. While thinking about this anchor, be specific – not just improve life or make things better, but detail how and why things will improve. Use SMART (Specific, Measurable, Attainable, Realistic, Timely) objectives if it helps.

2. Understand and adapt to the world around you

Successful collaborations recognise and adapt to the individual requirements that the end user operates in. It is key that we are fully aware of the reality of people's lives, from the ever increasing system pressures that healthcare professionals operate in, to the difficulties for patients with English as a second language. Unsuccessful projects often create great outputs, which are unworkable as a result of specific nuances that were not uncovered during the creation of the project. Generating deeper insights during research into the end user is key, also consider cocreation with your end user to ensure suitability.

3. Be in it together: Win or lose

In a truly successful collaboration, all involved have to be equally prepared to fail or succeed together. While it is all too easy to fall into repeating the same safe tactics, being prepared to undertake something which has not been done before often leads to the greatest success. Newer, collaborative approaches of course carry the risk of faltering as you have to move more people, from more organisations, collectively to a common goal. However, how effective will the outcome be and what will have been missed without external viewpoints? Therefore, to wholeheartedly approach this, it does require a collaborative win:win or a lose:lose attitude, where everyone involved is open-minded that both success and failure must be shared equally among partners. Without a collaborative attitude, able to handle success or failure, it is near impossible to have the full genuine commitment of all partners. Secure it from all and the best work will be achieved.

The future is now:

Collaboration is often talked about and discussed, but all too often, adversarial, polarised and competitive views force people to resist real collaborative partnerships. The case studies we have cited are a few exceptional examples of how we can do better. Truly being open to working with different partners is vital to the future of the health system. While we are bombarded with negative stories and opinions about industry involvement, there are people out there striving to do good, working together each and every day to improve health. These are people we should focus on, and these are the lessons we should learn. A time will come soon where we need to admit that the problems facing the future of healthcare have simply become too complex for one group to tackle alone. There is just too much to be done. Our way forward is understanding each other, through finding a middle ground, and taking on a genuine collaborative approach where we win and lose together.

Chapter 3

Collaboration – a way of thinking, working, living



Introduction

Through our exploration of collaboration, we have found the following quote to resonate strongly:

"While there is widespread interest in and goodwill towards cross-sector collaboration, industry and NHS stakeholders have frequently been frustrated by the time taken to agree collaborations, concerns about governance and the challenge of aligning system needs with industry offers."

This quote, taken from a guide jointly published in May 2019 by the Academic Health Science Networks (AHSN) and the Association of the British Pharmaceutical Industry (ABPI)⁵⁶ has been replicated in what we have read and repeated by the experts we have spoken to.

The value of open-source thinking

Drug development is fiendishly tricky, unpredictable and costly. Recent data demonstrate that academia-industry collaborations lead to higher success rates in drug development compared to academic noncollaborations.⁵⁷ Less attention is paid, however, to the importance of collaboration in ensuring patients get access to approved drugs. In fact, this is often where criticism of collaboration is levelled. Given the examples of best practice we showed in chapter 2 of this report and those in the <u>AHSN/ABPI</u> publication, it seems a naive and retrograde step to move away from this collaborative focus throughout a drug's lifecycle.

The reality needs to focus on streamlining, updating and improving working together, both transparently and cost-effectively, with a strong emphasis on publicly learning lessons from both the successful examples and those that did not hit the mark. An excellent example of openly learning lessons can be seen by AstraZeneca's publication of their '5R framework'. This framework was a cornerstone of a revised drug development strategy to help focus decision making on the right targets. As a result of this strategy, success rates from candidate drug nomination to phase III completion improved from 4% in 2005–2010 to 19% in 2012–2016. AstraZeneca published this information,



"in the hope that our experience could be useful to other companies tackling R&D productivity issues."58

Moving away from R&D productivity and phase III completion rates, this fundamentally means patients may be able to get access to, and have their lives changed by, innovations they otherwise may have missed out on. This example provides a gold standard of what can be achieved through improvements in one's work and then sharing it with the wider world, for the good of all. Parallels can be seen with the progression of sharing of data from clinical trials, in which industry has redoubled its efforts and made significant improvements.⁵⁹

This type of thinking is echoed in the 2017 Life Sciences: Industrial Strategy report to Government from the Office for Life Sciences. This report recognised that to achieve the best outcomes for the NHS and ultimately patients,



"a new philosophy of collaboration and trust must be an underpinning principle of the Life Sciences Industrial Strategy."⁶⁰

What this shows is that, in order to capitalise on the enthusiasm for collaboration we, as an industry, we need a greater focus on knowledge sharing and discussion about what leads to success. This will be the cornerstone of creating the groundswell of collaboration that so many are calling for.

Common themes of successful collaboration

Throughout our work and conversations for this report, and drawing on our own experience, three key themes have consistently been raised as being fundamental to effective collaboration.

Patient involvement unlocks the greatest insights

No matter who we spoke to or what we read, the most consistently discussed topic was the importance of having patients as the focus of the work. It is now widely accepted that patient involvement is crucial throughout all aspects of the life cycle of a drug.⁶¹ It is heartening to see a drive towards genuine collaboration with patients throughout healthcare systems and in particular in medicine development, even at the earliest stage of clinical trial design.⁶² Over the last decade, Aurora has been helping clients work with patients from this early stage of drug development, right through to patient support programme development and we have experienced first-hand the increasing degrees of true partnership and engagement over this time.

Later in this chapter, we touch on the debate about the payment from industry to patient organisations, and why when undertaking this type of activity, industry must have robust procedures in place to document patient involvement. It is important that industry does not shy away from compensating patients for their work, as they would with any other expert consultant. The move towards acceptance of patients as more than passive recipients of treatments to experts on a par with healthcare professionals and researchers, in our opinion, promises to revolutionise both clinical research, and drug and non-drug treatment options. While not a complete fix-all solution, more in-depth understanding of validated patient-reported outcome measures (PROMs) and patientreported experience measures (PREMs) allow us to move beyond a pure clinical outcome measurement and towards a more holistic patient-focused measurement, which in turn can lead to service improvement.63 Involving patients in the creation of clinical trial protocols can help yield the real-life data now required for continued reimbursement in some countries before the drug has even been approved.

2 Technology is not the answer – yet

With an expected budget in 2019/20 of £123.2 billion, the NHS employs 1.5 million people and deals with more than 1 million people every 36 hours.^{64,65} Within the biopharmaceutical industry, there are 573 enterprises and 63,000 people employed in the UK.⁶⁶ Over 870,000 people participated in health and social care research across England in the past year.⁶⁷

These are just some of the numbers which demonstrate the complex system in which we all have to access healthcare. The concern from some quarters is that central funding is not keeping pace with demand.⁶⁸

While the complexity of healthcare seems set to increase, there have been concerted efforts to improve the speed and cost of drug discovery. New screening methods,⁶⁹ specific peptide-focused targeting⁷⁰ and open sharing of data to encourage crowdsourcing of new targets⁷¹ are all examples of harnessing advancing technology collaboratively to improve drug development. While technology will undoubtedly prove a significant driver in the future of drug development, it is most certainly not a panacea yet.

IBM Watson, promising rapid and cost-effective breakthroughs in drug discovery, has struggled to deliver and is seemingly destined to refocus its efforts in clinical development, rather than drug discovery.⁷² More publicly, concerns have been raised about the integration of the remote consultation app Babylon, with the NHS-funded offering GP at Hand. Despite the public backing of Health Secretary Matt Hancock and positive experience for users and GPs,⁷³ criticisms about its ineffective AI symptom-checking chatbot⁷⁴ and its financial impact on local Clinical Commissioning Groups⁷⁵ have hit the headlines. While it is always exciting and interesting to see technological disruption, we should be cautious and remember that "fail fast" mantra of Silicon Valley needs to be amended significantly for healthcare.76

Fundamentally, the current model of healthcare provision is unsustainable, and we all have a role to play in improving it. Improvements must be driven through a collaborative and open conversation between industry, public sector and the public about what we can achieve and what role we can expect to play. Technology will undoubtedly change the system for the better in the medium-to-long run. However, investment in people must be the prime focus for now. As pointed out by the Health Service Journal, *"it remains unclear whether technology can help with the most urgent challenges faced by the NHS and its patients."*

3 Transparency is needed at every stage to engender public trust

While transparency is often talked about in terms of tracking payments to healthcare professionals and potential conflicts of interest, there is also a need for increased transparency in another regard. With the high cost of failed drug development, there needs to be greater transparency from all involved to increase public awareness of the complexity of the journey of the molecule to product and beyond into education and marketing, to make people aware of this. For example, it has been estimated that the total costs of an Alzheimer's disease drug development programme are \$5.7 billion, with the process taking around 13 years from preclinical studies to approval by the FDA.⁷⁸ Despite this estimation, it should be noted there have been no successful drug candidates which truly tackle Alzheimer's Disease at this time. We must be transparent about this cost, and time, impact on a company. Commercial organisations should be able to have open conversations about what this means for investment and future-proofing the company. This is especially important to encourage research in notoriously high risk/high failure fields, with Alzheimer's being the standout example of this.

With regard to potential conflicts of interest, early this year saw the publication and subsequent coverage of a BMJ article entitled *"Exposing drug industry funding of UK patient organisations".*⁷⁹ It discussed the limited transparency and commercial focus of industry payments to patient organisations. The authors suggest some helpful structural solutions, such as creating a shared corporate funding pool detached from commercial objectives and public grants.⁷⁹ It is good to see discussion around what is and is not appropriate and important for industry to fund with regards to patient organisations. Greater transparency can also lead to more robust reporting, as it has

been reported that there is a lack of consistency between different data sources when looking at payments to organisations.⁷⁹

The crucial point throughout this discussion about transparency is that without it, we give license to people to lie, deceive and take advantage of the vulnerable. This deception is most apparent in the anti-vaccination movement. A peer-reviewed article earlier this year, which mapped variables centred around the anti-vaccination sentiment on Facebook, found the second most common topic in these types of posts was "media, censorship, and 'cover-up." This 'cover-up' specifically included pharmaceutical companies not disclosing adverse events related to vaccines.⁸⁰ These charges are something we have commonly seen when looking at these 'mainstream' conspiracy-driven conversations; there is often a double focus. Firstly, claiming a cover-up of data (either as a 'cure' or related to adverse events) and secondly, around 'paying off' healthcare professionals in order for them to be puppetlike mouthpieces for industry. The increase in transparency around payments and data sharing, along with associated communications, can arm us with a crucial weapon to fight against something that has led to a rise in measles of 300 per cent.⁸¹ Regardless of where we sit within the healthcare system, we can surely be united in tackling this.

The Age of Enlightened Self-Interest

The Age of Enlightenment was an intellectual movement during the 18th Century, which centred on reason as the primary source of progress.⁸² Enlightened self-interest is a philosophy which can simply be described as 'doing well by doing good'.⁸³

Looking at the data, people are not principally dying because of ill health. If we look to the US, their life expectancy has unfortunately been falling, largely not because of cancer, cardiovascular disease and other chronic conditions but because of suicide, alcohol and drug addiction.⁸⁴ Even discounting these societal problems and focusing on medical conditions, data show us that of 56.9 million global deaths in 2016, 40.5 million (71%), were due to noncommunicable diseases, a large percentage of which are preventable.⁸⁵

Given we have made such great strides in treating other illnesses, we believe we are entering a time where there is a broader role for a partnership between industry and society. This is an era where industry can use their intellectual and financial power to prevent the preventable, and ensure we are spending our money on the unavoidable. If we reduce our health expenditure on preventable illness, we can concentrate more on tackling genetic diseases, the unpredictable and accidents and move towards a future with fewer lifelong conditions. Ultimately public health systems only have so much they can do on a societal level, therefore industry could have a significant role in improving public health, be it out of selfinterest or not.

We are by no means the first to suggest this, the NHS in Manchester has been partnering with the pharmaceutical industry across a variety of projects to improve local health. In 2018, Richard Mason, co-founder of The Foundation Institute for 21st Century Medicine (C21Med), dubbed this situation enlightened self-interest.⁸⁶

To ensure the use of the inevitably high-cost treatments that are arriving at the doorsteps of regulators across the globe, perhaps now is the time for the industry to help free up budget through greater collaboration with not only the NHS but the wider public sector, through a variety of unique collaborations focused outside their direct product portfolio. It may well be met with inevitable criticism, but it can work, and we can all win. Given the evidence regarding the social determinants of health.⁸⁷ might we enter a brave new world where we see the pharmaceutical industry funding improved housing and school meals for under-privileged families, which reduces non-communicable disease, and therefore the NHS burden so we can spend an increased proportion on advanced therapies? With seven million people living in persistent poverty in the UK,⁸⁸ perhaps the best

thing anyone who cares about health outcomes can do to improve them is to invest in social infrastructure. It is a bold idea, but we have the chance to change our approach, and as we enter 2020, perhaps this can be the time we also begin to enter the Age of Enlightened Self-Interest.

Collaboration is in our hands

In chapter 1, we highlighted headlines like "Scandal of experts who rule on NHS statins but get paid by drugs firms."³ which paint a picture of an underhand financially dominated relationship. It is this that the public will take away when they think about the collaboration between the pharmaceutical industry and healthcare professionals.

With the information presented as it currently is, it is unreasonable for us to expect the general public to have the context about the complexity of the drug development process and clinical trial programmes. They will not be presented with the background as to why these experts are involved in many different things, or why they may be the best placed to undertake multiple roles, acting as a bridge between the NHS and industry. Regardless of our nuanced beliefs about collaborative working, it is unhelpful and somewhat offensive to portray hard-working and dedicated healthcare professionals as selling out their patients' health and the Government purse for a quick buck.

Because of the general lack of understanding of the drug development and assessment procedure, all stakeholders in healthcare, regardless of their personal opinions, need to be committed to better and more effective communication to the general public. Without context, we cannot expect society to make informed decisions about the best use of innovations. For example, the pharmaceutical industry should focus on more significant media and public engagement in explaining the drug development process and why healthcare professionals may act as paid consultants throughout this. Similarly, NICE should continue to be publicly open about explaining how they assess the cost-effectiveness of a new treatment and why they make certain difficult decisions.

All of us on an individual basis also need to be better at communicating with the public. Many routes exist to do this, from science festivals and media appearances, to working in schools or being a part of public debates and even the very British approach of chatting in the pub. If we all take the time to do this, we will present the public with a broad perspective of the depth and breadth of views in healthcare and help them understand why collaboration is essential. An improved conversation will also help move this somewhat controversial topic, which is often subject to 'mud-slinging', to a more reasoned societal level debate, which is where it belongs.

Collaboration – a way of thinking, a way of working, a way of living

With the previously mentioned media narratives playing out, it is easy to view the world with a negative outlook. However, we should remember that we are continually making strides forward. As recent popular science books by Steven Pinker⁸⁹ and the late, great, Hans Rosling⁹⁰ have demonstrated, the world is improving, and we should never forget that.

We genuinely believe that collaborative working can lead to further great things. We have seen an evolution in dealing with potential conflicts of interest in recent years, with publications listing funding sources, speakers listing their funding on slides, the advent of Disclosure UK, which tracks payments from the pharmaceutical industry to healthcare professionals and organisations. However, more needs to be done both within healthcare and on a societal level to agree on a way forward to encourage collaboration while ensuring impartiality and objectivity.

We must ensure there is an open discussion of all potential conflicts, including industry-focused and personal ones, for example popular book, media and social media points of view, which may affect an opinion or remove independence,

even resulting in outright dogmatism. Hopefully, this can lead to more open and respectful conversations.

Pharmaceutical companies must work harder than ever before to thoroughly conduct needs assessments to understand what healthcare professionals genuinely want for their patients to gain access to innovations. No longer can it be permissible not to provide significant additional value to the healthcare system. With healthcare professionals expected to perform better with less and less resource, it is time for the industry to help enable this. Rather than solely focusing on behaviour change, as it seems to be the standard, maybe we should shift our thinking towards a focus on how to use technology and educational strategies to allow healthcare professionals to make the best evidence-based decisions. With the belief that as long as the benefits are understood and access is enabled, healthcare professionals will inherently want to use innovations that truly make a difference. Industry needs to move away from asking "How can we improve our reputation?" to a position of "How can we do good in society?". If this is the first question to be asked, reputation will surely follow.

Similarly, the pharmaceutical industry has helped provide ground-breaking and life-changing medical innovations. To optimise patient access to these innovations, healthcare professionals and other commentators need to be willing not to dismiss their views automatically or presume nefarious intent.

Revolutionary treatments are no longer just on the horizon; they are here. They will continue to be expensive and sophisticated and, as we surge ever forward into the 21st Century, we stand at a time whereby a leap of faith is required on both sides, to work together with one common goal in mind — improving patient outcomes in the most cost-effective manner. By working together, all stakeholders can contribute to improving the lives of people suffering from illness, both chronic and acute. What we care about is working towards something better, whatever the result at the end. Aurora genuinely believes in a collaborative future and hopes that whatever one's view we can have a respectful conversation about it.

The title for this report, 'Alone we can do so little, together we can do so much', was chosen on purpose. In the early 20th Century, Helen Keller said this, and it is a quote which truly stands the test of time. We are facing a time of unimaginable advances in technology, science and medicine, and our world will change in inconceivable and immeasurable ways in the coming decades. At the same time, so much throughout our lives is seemingly aimed at driving us apart, and we must not let that happen. Social media-driven tribalism has the potential to lead to a society whereby nuance, subtlety and comprise disappear — a society where you are either with me or against me.

We will not achieve what we can, and we will not live our longest and best lives without greater understanding, empathy and collaboration. This applies to healthcare, more than anywhere.

The future is now:

We are committed to finding practical and implementable solutions to improve collaboration across healthcare. Whether our own or other people's, we are seeking to share and implement best practice examples of collaboration in healthcare.

If you have any comments, questions or examples to share with us. Please get in touch.

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About Aurora Healthcare Communications and collaboration:

Aurora is a strategic communications agency specialised in health. As a group of people, we do what we do because we genuinely want to make a positive difference not only to our clients but to healthcare and society as a whole. We have a deep-rooted belief that collaboration across borders, disciplines and beliefs is the key to helping to address our healthcare challenges.

Our team has an award-winning approach to collaboration, helping guide multiple stakeholders to a common goal. We also have a specific patient involvement and engagement service to help businesses co-create initiatives big and small to secure better patient outcomes. In 2018, our work in an exciting collaboration not only helped people with inflammatory bowel disease secure better access to toilets throughout the UK's main travel hubs (airports, rail stations, service stations) but raised public awareness that not every disability is visible. We were very proud to win the Excellence in Healthcare Collaboration and Partnerships at the Communiqué awards. More can be found out about the project here.

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