Conclusion

From all our discussions it is apparent that there is great potential for the future of patient data but also lots of challenges. There are many patient benefits as well as multiple additional opportunities for the broader community to bring to the sector. These may include hospitals, health systems and existing healthcare organisations, not to mention a host of new companies – many with deep pockets and sophisticated technology.

While there are many with global ambitions, for now it seems that change is most likely to occur at a more regional level. Whether because of data sovereignty, differences in privacy regulation or varied levels of trust in governments, healthcare providers and big-tech, it looks like progress will be in fits and starts with a localised or sub-sector focus. The end-goals of more widely shared information about patients driving a transformation in healthcare are credible and there is general agreement on the ideal destination, but the journey for many is going to be bumpy.

With all the developments in place, it is clear that healthcare is getting more personalised, more patient-centric and ever more data-driven. The investments being made across the sector by governments, pharmaceutical firms, IT companies and multiple new entrants not only support the direction of travel but are also building momentum. In some key regions there is both the opportunity for change and increasingly supportive regulatory environments that will encourage better integration, interrogation and control of patient data. China and India are, in many eyes, the ones to watch but

equally other more mature and 'joined-up' systems in Europe, Australia, Canada and Singapore are showing promise. Questions have to be raised, however, about the US. The world's most well financed healthcare system is also its most fragmented and so, from a data perspective, the one with most silos. That said it is the home of many of the big-tech firms that are seeking to change the healthcare status quo and so, as they focus their resources and analytics on the tasks at hand, there are many that see tangible progress on the horizon.

While this report has highlighted a wide range of both opportunity and challenge, and has sometimes focused on the potential for the key players involved, we must not lose sight of the main motivation for most people in the sector – the better care of the patient. While some of the issues addressed here have covered the changing privacy and data landscape as well as improving efficiency and effectiveness and so reducing cost, few have relevance without delivering clear advantage for those who most need better healthcare – often the weakest and most vulnerable in our society.

If we can align the multiple strands of this issue, over the next decade, patients will:

- Become more involved in their overall health and how to improve it

- Be provided with more tailored support, diagnosis and treatment

- Have greater control of their health data, even if they don't own it

- Be active and not passive in the creation and sharing of value, and so

- Live longer, healthier and perhaps even happier lives.

If we get it right, these benefits will be delivered for the many and not just the few.

As a project, this has been a hugely insightful experience for us and judging from the feedback we have received, it has also been useful for many of those who kindly spared their time to join in the discussions. Once more we thank all those who participated for their time and enthusiasm.

This report is openly shared in partnership with multiple organisations around the world so we hope that its global context and multi-disciplinary perspective will help more to see the opportunity through an informed lens.

There may well be significant challenge but there is also huge opportunity. We look forward to seeing the potential change that so many have talked about successfully delivered.

To follow this project further and access more information please see www.futureofpatientdata.org

Questions

From the discussions and insights gained from this project, it is clear that the future of patient data is ripe with both opportunity and challenge. As we look ahead it is also evident that some organisations and governments are more ready for the emerging shifts than others. To help provoke further dialogue and discussion, we have suggested a number of questions that could be addressed. We use these, and other stimulus, as part of follow-on discussions with individual companies, healthcare systems and governments. They may also be useful to you internally to help further challenge assumptions and identify new areas for potential innovation.

Cutting across many of the topics covered in this report we propose 5 key questions each for governments, companies, hospitals and doctors as well as individual patients.

FIVE QUESTIONS FOR GOVERNMENTS

1. What are the greatest risks from sharing of public and individual citizen health data?

2. What regulation would help to control the use of personal data by others?

3. Where best can advances in data be used to drive down healthcare costs?

4. Which are the top opportunities to really improve public health?

5. Should citizens data be contained within national boundaries?

FIVE QUESTIONS FOR COMPANIES

1. How can you build and maintain trust in an increasingly transparent market?

2. Which of your datasets can create wider social value from being made open?

3. What is the best way to gain consent to share patient data?

4. Where can more information and better analysis most impact your business model?

5. How would a disruptive new entrant most effectively destroy your business?

FIVE QUESTIONS FOR HOSPITALS

1. How can you enable patients to understand how to best manage their health?

2. What patient data are you prepared to share with others?

3. How can you leverage personalisation and individual data to better treat individuals and also benefit the many?

4. What skill sets do you need to make best use of AI in the future?

5. How will new competitors capitalise from more private health data?

FIVE QUESTIONS FOR DOCTORS

1. In what ways will better data best empower your patients to take control of their health?

2. How will more accurate data help your patients better prevent illness or better manage their recovery?

3. How can you help your patients understand what their health data is telling them?

4. How can AI help to improve the care you provide to patients?

5. Where will be the most significant change in the doctor / patient relationship?

FIVE QUESTIONS FOR PATIENTS

1. Are you ready to take control of your own health data?

2. Do you think your data can really be private?

3. Who do you most trust with your personal information?

4. Which health insights would lead you to change your behaviours?

5. How much do you think your health data is worth and should you gain from it financially?