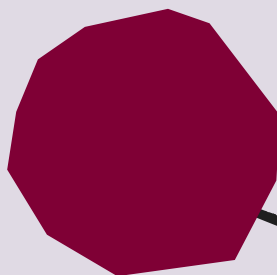
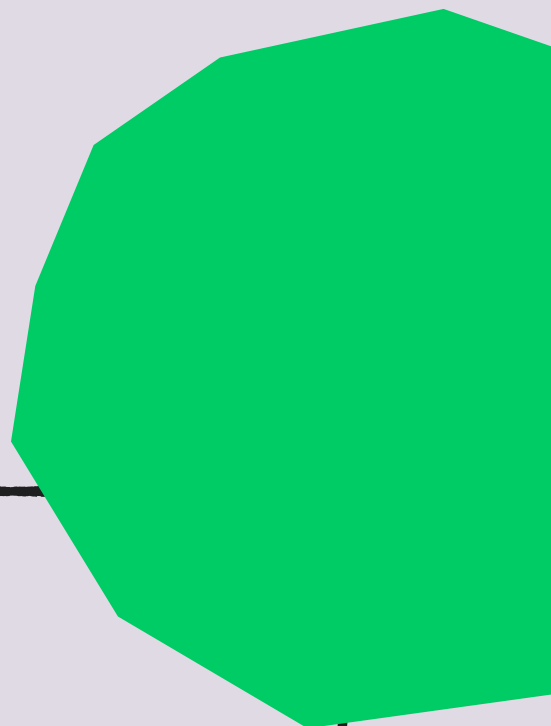




Working with data to improve access and address inequalities: Insights from the Q community

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April 2023



Introduction and contents

Between June and October 2022, the Q community undertook an action learning project with people using data to improve access and address inequalities in their work across different health and care settings. This approach supported learning by the individuals who took part and generated wider insights into this important topic.

This short report shares five key themes for making progress, alongside useful resources and tools for others doing or supporting similar work. It covers:

Why we did this work

The need to increase access; the need to address health inequalities; and the need to explore the role of using data to make progress on these two priorities.

How we did this work

By using action learning so that participants could explore these challenges and we could draw out wider insights.

What we found

We identified five overarching themes that need attention to support progress:

1. **Acting with urgency but recognising the need for a longer-term focus.** This includes being clear on the trade-offs between efficiency and equity, and balancing immediate action with more deep-rooted change.

2. **Collecting and accessing better data on waiting lists and inequalities.** Drawing on national data where possible but also investing in foundational data collection at the project level.
3. **Turning often imperfect data into action.** Recognising the psychological toll and anxiety this can cause and the time, capabilities, infrastructure and data literacy this requires.
4. **Recognising the benefits, and limitations, of applying a systematic improvement approach.** Improvement can play an important role in defining priorities and problems, engaging staff, and co-producing with patients. But those working in quality improvement (QI) need to apply much greater focus to developing tools and methods that directly support equity and equality.
5. **Collaborating with and learning from others.** Creating spaces and processes where those working on this topic can share challenges and solutions.

Conclusion

Acknowledgements

Find out more about the people who generously contributed their time and energy to this project.

References

Why we did this work

Part of Q’s overarching mission as we move towards recovery from the pandemic ([Pereira, 2022](#)) is to help the health and care system reduce waits in a way that supports broader transformation goals. This insight project explored three interrelated aspects of this wider theme: the need to increase access; the need to address health inequalities; and the role of using data to make progress on these two priorities.

The huge pressures around access to care in the UK and Ireland are well documented, including record-high waiting lists for elective care (eg [Blythe and Ross, 2022](#)), large hidden waits, and challenges accessing care across many other parts of the system (eg [NHS Confederation, 2022](#); [BMA, 2023](#)). This is causing considerable harm to patients. As Richard Murray, Chief Executive of The King’s Fund, recently lamented, ‘everywhere patients look there are simply too few services with too little capacity to treat and support them in a timely manner’ ([Murray, 2023](#)).

At the same time, evidence on the disparities in access and outcomes between different groups is becoming ever clearer, especially around ethnicity ([Robertson et al, 2021](#)) and socioeconomic deprivation, with gaps actually widening in some areas ([Finch et al, 2023](#)). This has led to louder calls for an ‘inclusive recovery’ (eg [NHS England](#)), with one report arguing that the NHS should give as much priority to reducing health inequalities as other areas such as waiting times and financial targets ([Robertson et al, 2021](#)).

The essential role of data in driving progress in these two areas is already understood, yet many reviews and reports critique the existing state of data (eg [Goldacre and Morley, 2022](#)). In fact, perhaps the primary motivation for undertaking this project was that in our previous insight work, the Q community has consistently identified issues around the collection, analysis and use of data as barriers to progress ([Scott and Cann, 2021](#)).

“Not so long ago, and we would have been happy with 85% spread or uptake... I don’t think we really realised that it was always the same 15% you were missing... It’s great that now we’re starting to look at the 15% first.”

How we did this work

Building on [our earlier work](#) on waits and the backlog, we set out to gain insights from people who are confronting the challenges of using data directly in their work. We used an [action learning](#) approach to give participants an opportunity to explore live challenges and issues with a group of peers in a safe and supportive space. We drew out insights and learning of relevance to others throughout the project. This included the two sketchnotes on the following pages. The [Action Learning Centre](#) provided expert facilitation.

Action learning is a group-coaching methodology that brings people together to solve challenges they are facing in real time. As Figure 1 shows, between June and October 2022, we brought together 14 participants to scope the issues they were facing. They then split into two action learning sets to explore these challenges in more detail.

Group 1 undertook four two-hour sessions and group 2 undertook three two-hour sessions.

Participants have kindly commented on and added to the insights shared in this report.

Figure 1: Our project approach



The 14 Q member participants (see Acknowledgements) were involved in a wide variety of projects using data to address inequalities and reduce waiting times. Their projects included work to reduce inequalities in access to cancer screening, eating disorder services, maternity services, ophthalmology and diabetes services, as well as a public health programme to address fuel poverty and housing quality. Although the projects addressed a wide range of inequalities, most focused on ethnicity or socioeconomic disparities. They were working at national, regional or organisational level and were based in the NHS, voluntary or academic sector. Most participants were not data specialists.

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Feedback from participants shows that the action learning sessions generated a huge amount of learning on the challenges facing their individual projects. These insights were surfaced and logged within the project, and participants made commitments to take those insights forward as part of the action learning process itself.

This report takes the learning from individuals' experiences and draws out insights for those leading and supporting similar improvement work. We present five overarching and interlinked themes that need attention if we are to significantly improve how we use data to address inequalities when tackling waits. Each section provides links to resources and tools to help if you want to apply these insights to your work.

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Figure 2: Sketchnote sharing emerging insights part one (July, 2022)
View the related [insight presentation on the Q website](#)

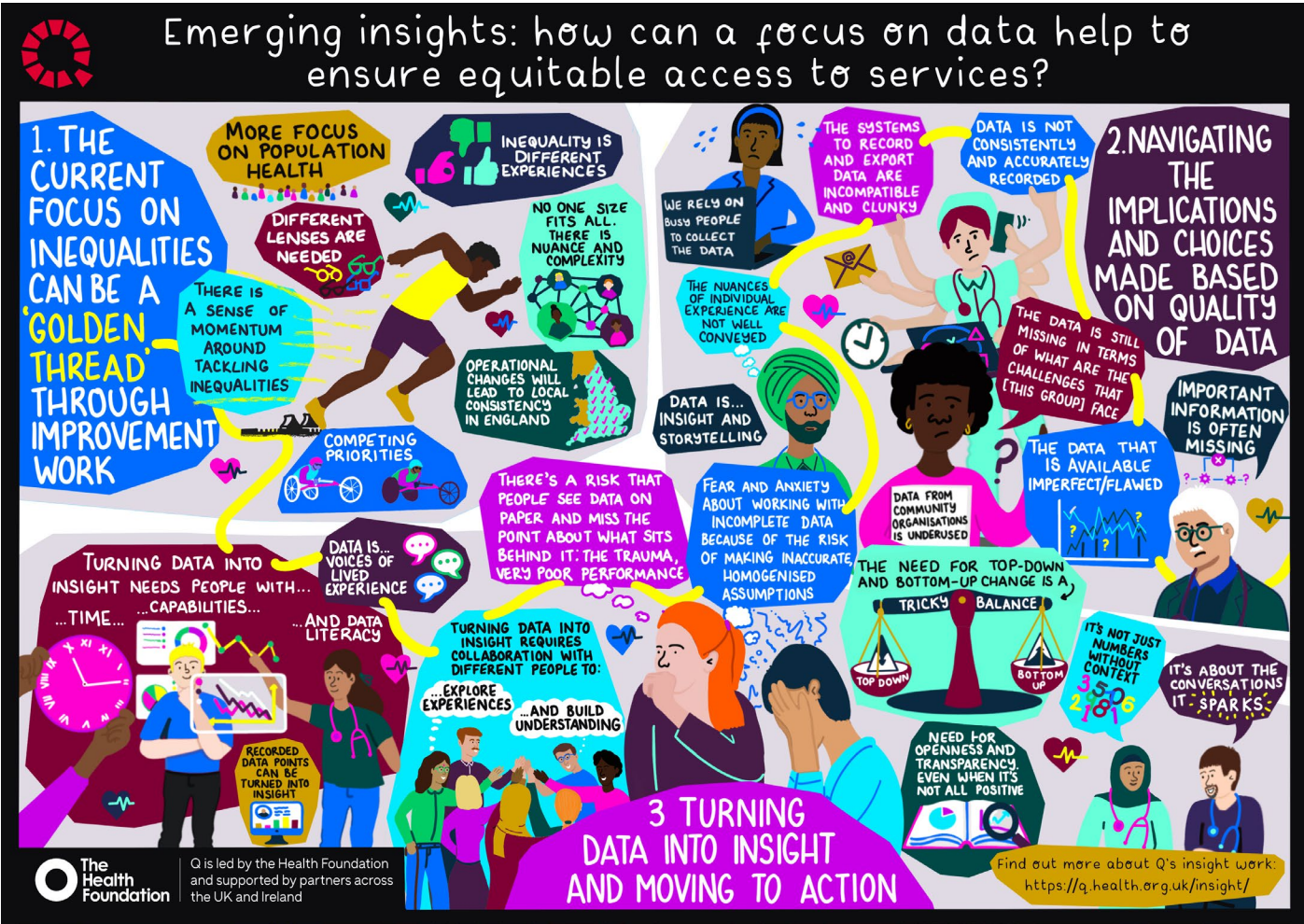
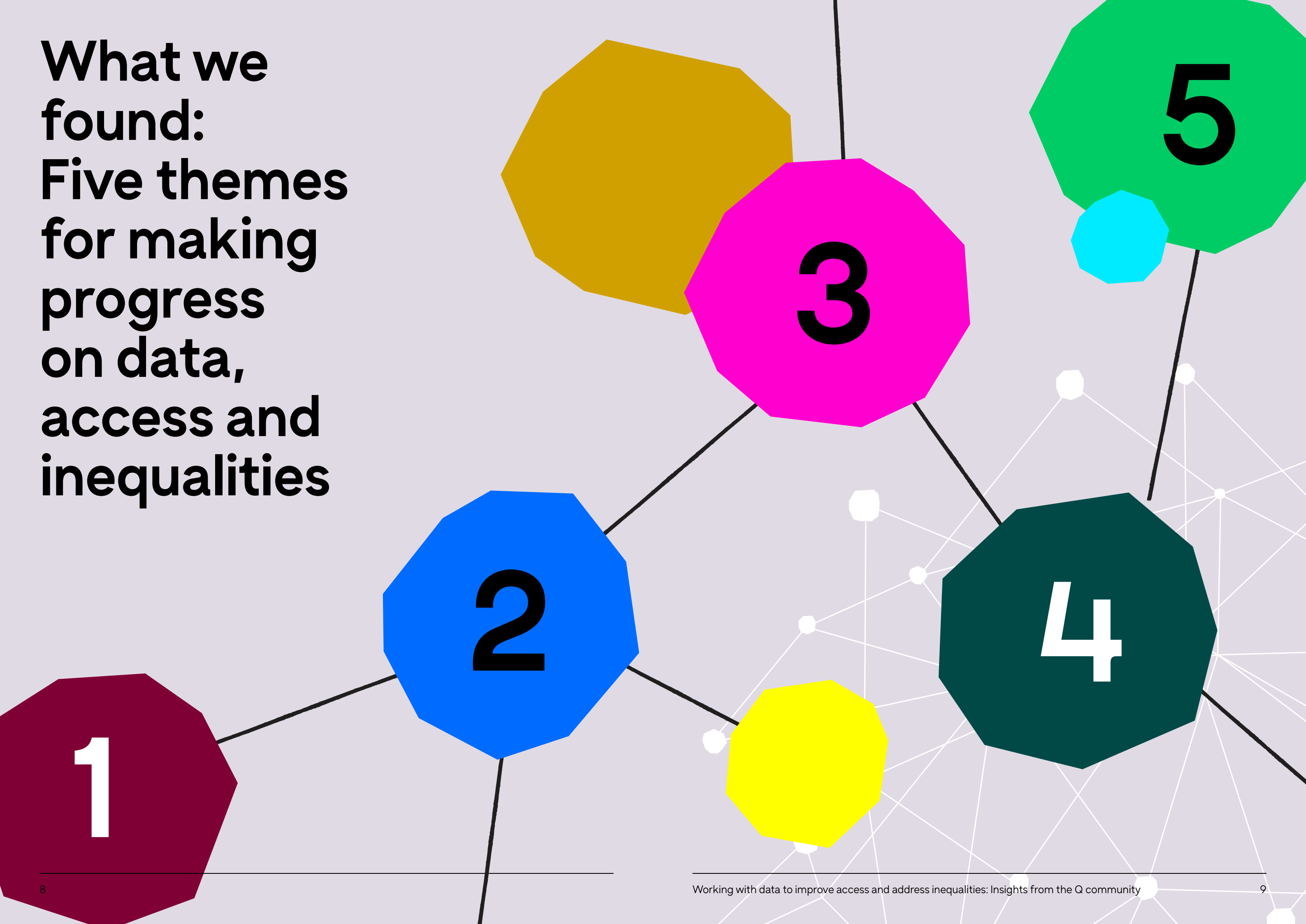


Figure 3: Sketchnote sharing emerging insights part two (September, 2022)
View the related [insight presentation on the Q website](#)



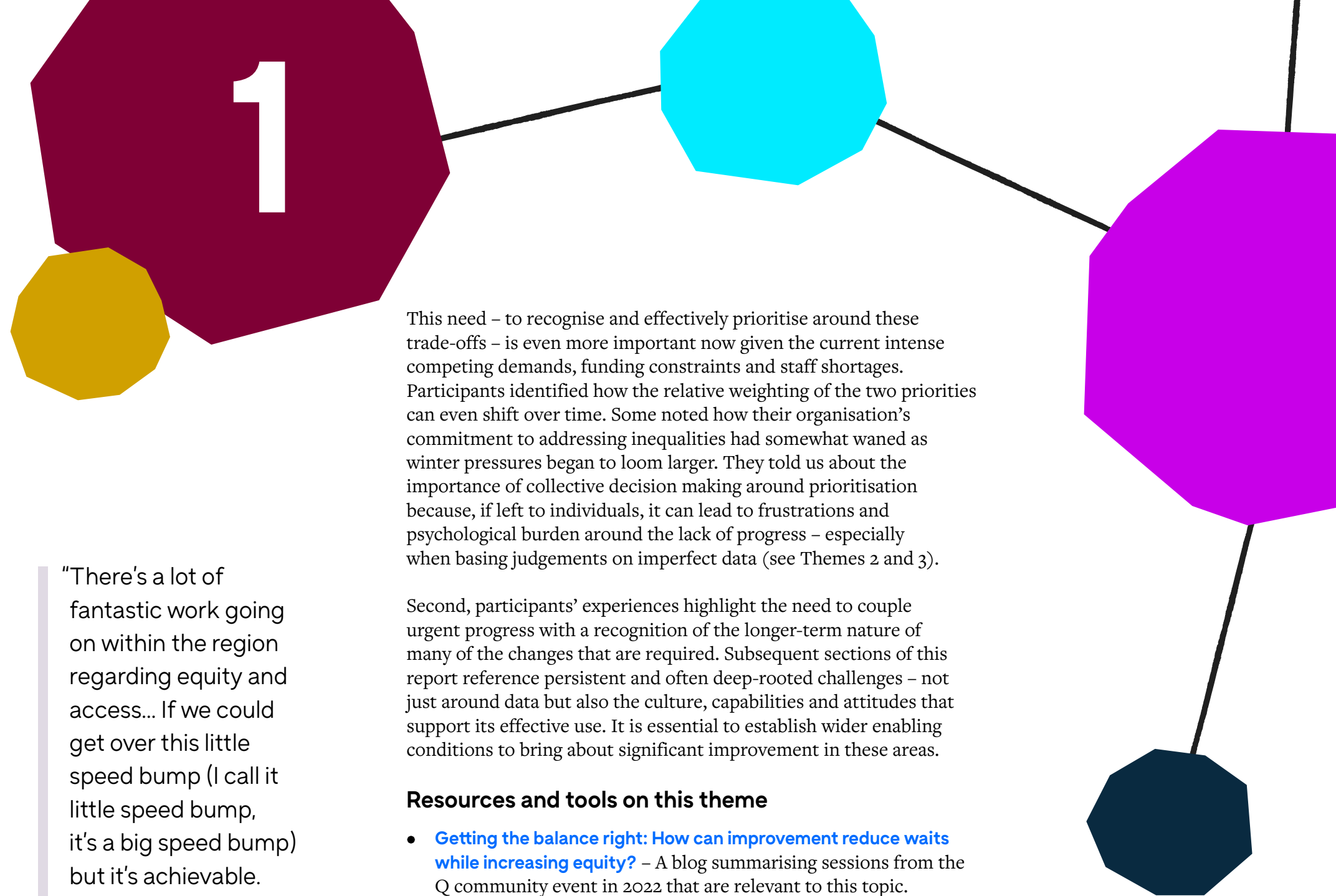
**What we
found:
Five themes
for making
progress
on data,
access and
inequalities**



Acting with urgency but recognising the need for a longer-term focus

Participants felt a palpable sense of momentum in their organisations and signs of change in the way people are thinking and acting to address inequalities – including in direct relation to waiting lists. As one participant put it, ‘There are lots of organisations working on this. It feels like there is a sense of urgency and like people are really willing to be collaborative and go above and beyond to learn from one another.’ Participants felt a strong sense of duty to harness this urgency and take immediate action where possible, believing that inequalities can become a powerful ‘golden thread’ through their improvement work. However, at the same time, they stressed that it is important to maintain a balance between immediate action and a focus on longer-term improvement goals.

First, there is a need to be explicit about the trade-offs involved between tackling waiting lists and addressing inequalities. Sometimes, considerations of equity and efficiency are mutually reinforcing but sometimes they are in tension. Participants recognised the role that good data can play in honest discussions about these trade-offs. At a [recent Q event](#), one leader working in this area warned that ‘there is ample clinical evidence out there... that tells us that a focus on waiting times alone drives inequality and none of us would want to see elective recovery coupled to widening inequality, but I fear that is where we are at the moment unless we take on this ambition [to reduce waits equitably].’



“There’s a lot of fantastic work going on within the region regarding equity and access... If we could get over this little speed bump (I call it little speed bump, it’s a big speed bump) but it’s achievable. But if we could get over this, things will fall into place.”

This need – to recognise and effectively prioritise around these trade-offs – is even more important now given the current intense competing demands, funding constraints and staff shortages. Participants identified how the relative weighting of the two priorities can even shift over time. Some noted how their organisation’s commitment to addressing inequalities had somewhat waned as winter pressures began to loom larger. They told us about the importance of collective decision making around prioritisation because, if left to individuals, it can lead to frustrations and psychological burden around the lack of progress – especially when basing judgements on imperfect data (see Themes 2 and 3).

Second, participants’ experiences highlight the need to couple urgent progress with a recognition of the longer-term nature of many of the changes that are required. Subsequent sections of this report reference persistent and often deep-rooted challenges – not just around data but also the culture, capabilities and attitudes that support its effective use. It is essential to establish wider enabling conditions to bring about significant improvement in these areas.

Resources and tools on this theme

- [Getting the balance right: How can improvement reduce waits while increasing equity?](#) – A blog summarising sessions from the Q community event in 2022 that are relevant to this topic.
- [Achieving health equity: A guide for health care organizations](#) – This White Paper from the Institute for Healthcare Improvement (IHI) provides guidance on how health care organisations can reduce health disparities.
- [A prioritisation matrix developed for NHS Education for Scotland](#) – A prioritisation matrix is a table for ranking ideas or projects in order of importance, using pre-defined criteria and weightings.
- [Prioritisation tools in QI](#) – A short video from IHI that explains a priority matrix and how to interpret the results.
- [How-to guide: Equity-focused quality improvement](#) – A very short guide from the University of Cambridge and the Eastern Academic Health Science Network on the steps involved in equity-focused QI.

Collecting and accessing better data on waiting lists and inequalities



Participants in the project raised persistent challenges around accessing high-quality data, noting that this was a key barrier to progress in their work. Challenges included:

- missing data, such as key records not being consistently or accurately completed in their organisation
- fragmented data due to systems for recording and exporting data being incompatible, or information governance being seen as overly restrictive
- qualitative data being undervalued and not sufficiently integrated with quantitative or routine data
- data that lack the necessary nuance to accurately describe the complexity and intersectionality of different experiences of inequality.

These insights add weight to the well-documented issues identified in the wider literature around data quality. This includes the recognition that ‘understanding is limited by a lack of good-quality data and analysis’ ([Robertson et al, 2021](#)) as well as a wide range of recommendations for how to improve data across health and care. A review by colleagues within the Health Foundation broadly welcomed the direction of travel outlined in the latest NHSX data strategy and the [Wade-Gery review](#), but explicitly asked for the plans to go further in ‘how data are used to understand and address health inequalities’ ([Keith et al, 2022](#)).

“The data is still missing in terms of what are the challenges that [this group] face.”

“One thing I find frustrating is the inelegance of data. What we tend to do, or what data tends to do particularly around ethnicity data, doesn’t capture the nuances and the intersectionality of what we need to know. And it leads us to make some lazy assumptions about people... It hides important things that sit behind the data.”

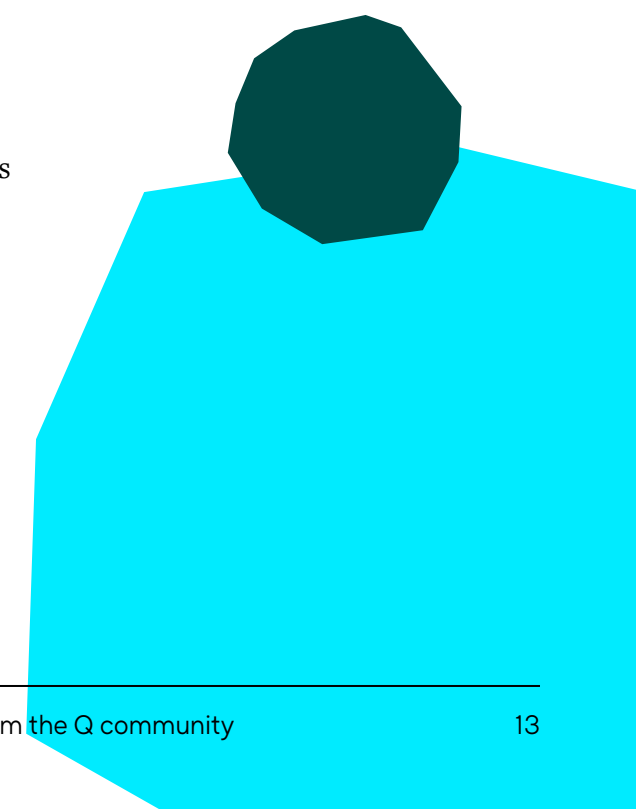
These calls to improve data at the national level should be heeded and some participants called for much greater coordination and consistency at the national and regional level. But participants’ experiences also underscore the everyday reality of working with imperfect data at the individual, team and project levels. Some participants were shocked by their inability to access even very basic data – often because it simply was not collected. Others identified significant gaps in their own understanding of what data to collect and the skills needed to collect it effectively. There are certainly opportunities for those working in this area to draw on large datasets and improved national-level analysis, but organisations also need to make rapid progress on the fundamentals of good data collection practice.

Resources and tools on this theme

- [How better use of data can help address key challenges facing the NHS](#) – This long read explores how the NHS in England can better use routine health data to help address current challenges, including winter pressures, and the growing elective care backlog.
- [The Healthcare Inequalities Improvement Dashboard \(England\)](#) – The dashboard covers the five clinical areas outlined in NHS England’s [Core20PLUS5](#) approach. It aims to provide rich data, insights and evidence to narrow health care inequalities and complement data available from other national programme teams, as well as organisations working to narrow health inequalities.
- [Making data count: Getting started](#) – An interactive guide for people responsible for analysing, interpreting and presenting data to others, and for decision makers who need data to answer questions.
- Two reports that explore the quality of ethnicity data in England:
 - [Ethnicity coding in English health service datasets](#) Nuffield Trust, 2021.
 - [Understanding consistency of ethnicity data recorded in health-related administrative datasets in England: 2011 to 2021](#) Office for National Statistics (ONS), 2021.
- A range of resources for capturing demographic characteristics of patients and users:
 - [Using demographic data – A downloadable guide from Healthwatch.](#)
 - [The power of language – A consultation report on the use of collective terminology at the NHS Race & Health Observatory.](#)

“It’s that link between data and action. I don’t want to be negative but if you can’t get access to the data, it’s hard to know what action you should take and [what] direction you should go in.”

“There’s a risk that people see data on paper and miss the point about what sits behind it: the trauma, very poor experience. It’s about treating stories and experiences with respect.”



Turning often imperfect data into action

Perhaps the most important insight from participants, and one that will resonate with many others, is around the challenges of trying to act on the imperfect data that are available.

First, we heard that participants can be fearful and anxious about making inaccurate, homogenising assumptions based on the limited data available to them. This undermines their confidence and leads them to question their ability to make analytical judgements or to understand issues from other people's perspectives. We heard how acting on imperfect data can raise anxiety and take a psychological toll on those leading this work. Doing improvement work requires a willingness to acknowledge individual and organisational vulnerability and uncertainty. Organisations need to support staff to continue to take action where necessary.

Second, and related to Theme 1 (the tension between urgent action and a longer-term focus), some participants are wrestling with where to start in their work. Should teams start work with imperfect data and then involve people that can help challenge assumptions and deepen their understanding as work progresses? Or should they invest time upfront to improve the data, so they are more confident of their starting point? The answer will differ depending on the service, the exact state of available data, and the needs of service users.

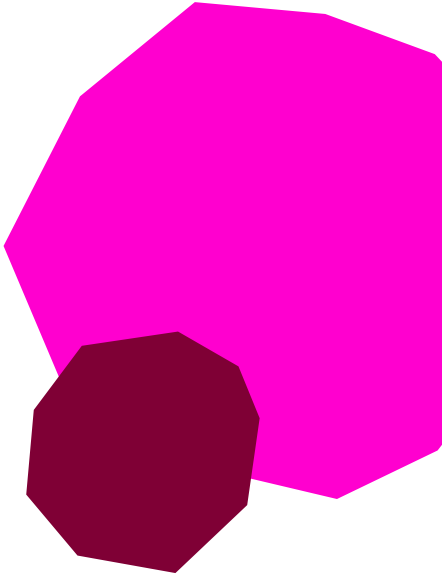


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Third, participants indicated that while having quality data is vital, it is not necessarily the most important requirement when it comes to action. They told us that turning data into action requires people with the time, capabilities, infrastructure and data literacy to explore and interrogate the data, to make analytical assessments, and to know when to collaborate to explore different experiences and build understanding. We also heard how the broader surrounding culture has an influence – for instance, on how decisions are made about what to prioritise and who is involved; and on how change is perceived and received. This echoes the findings of a recent report on learning health systems, which are a systematic approach to iterative, data-driven improvement ([Hardie et al, 2022](#)). The report makes recommendations on how to better understand the needs of people and their communities, and how to improve the curation and visualisation of data so that it is easier to understand and act on that data.

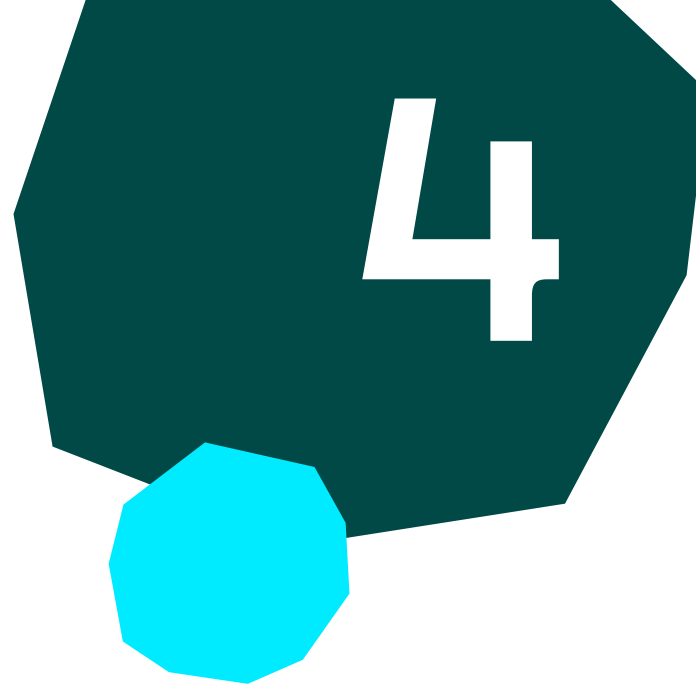
Resources and tools on this theme

- [Developing learning health systems in the UK: Priorities for action](#) – This Health Foundation report suggests there is a large gap between the promise and practice of learning health systems.
- [Poverty and the health and care system: The role of data and partnership in bringing change](#) – This long read by The King's Fund and the Centre for Progressive Policy sets out the data available, explores existing good practice, and what needs to happen next.
- [Apply social value judgements to tackle inequalities](#) – Professor Kiran Patel talks about health inequalities, population health and digital delivery.



"You often think you're doing the right thing in the right way, but the perception and translation is a [minefield]... People come at things from different perspectives, and you think you are doing the right thing and taking the right approach, then you get a complete curveball."

Recognising the benefits, and limitations, of applying a systematic improvement approach



Many participants were working at a local or regional system level to embed collaboration, share with purpose, and align priorities and outcomes. Some described the difficulties of embedding a top-down change to be owned and shared at organisational and team levels. This is especially true when working at a distance from local teams and when individuals have limited influence over how changes are implemented in practice.

In response to these challenges, participants highlighted improvement principles and methods that were helping them make progress in this area (these are in addition to the more data-focused improvement tools we discuss elsewhere in the report):

- Tools that support systematic prioritisation, including between waits and inequalities, and between the short and long term.
- Tools that help to effectively diagnose ‘the problem’. This includes creative approaches to overcoming barriers to progress around inequalities such as historic cultures, ways of working, behaviours, and a lack of infrastructure for sharing data.
- Tools for communicating with and engaging staff, and creating channels for feedback. It is vital to share what is happening and why, and to create opportunities for feedback.

Some participants also identified the need to bolster their approach to co-design – with this insight often emerging through the action learning process itself. Improvement can provide useful tools for involving those who are ‘closest’ to the issues in defining the problem and developing solutions. Notably, while developing actions in response to the challenges they faced, some participants identified more sophisticated and substantial engagement with patients and

“Some people will see data as the answer to everything. But just knowing the numbers isn’t the answer. You have to actually engage with people, to know more about what the issue is.”

service users as a way to challenge some of the biases they may hold around equality and equity. This co-production was seen to help with: understanding what data were required to inform decisions; developing solutions for collecting that data more effectively and efficiently; and building confidence among patients and service users about why the data were being collected.

At Q, we are confident that improvement can play an important role in making progress on access, inequalities and data. However, we must temper this confidence with humility, and recognise that within improvement itself there is a need for a much more concerted focus on inequalities. Although equity is included in most core definitions of improvement ([eg Jones et al, 2021](#)), ‘it is often the most overlooked aspect of quality compared to safety, effectiveness and efficiency’ ([Ford et al, undated](#)). Indeed, ‘traditional QI methods can maintain or worsen health inequities across subpopulations’ ([Hirschhorn et al, 2021](#)). Our project has reaffirmed the need for all of those working in improvement, including the Q community, to show greater ‘strategic intent’ ([Feeley, 2020](#)) in this area. Progress will require proactively developing improvement tools, methods and approaches that support equity and equality much more effectively.

Resources and tools on this theme

- [Equity, health inequality and quality improvement](#) – This paper was originally developed as an internal working document for Healthcare Improvement Scotland staff to inform discussions around QI planning and measurement, but was then shared externally.
- [Bringing equity into QI: Practical steps for undertaking improvement](#) – This report from the Center for the Health Professions at the University of California includes a section on using data differently.
- [Aiming beyond equality to reach equity: The promise and challenge of quality improvement](#) – A BMJ article drawing on learning from the Ethiopia health care quality initiative to make recommendations for how the QI community can increase its equity focus.
- [Guidance on co-producing a research project](#) – Guidance and resources from the National Institute for Health and Care Research (NIHR).
- [A co-production model: Five values and seven steps to make this happen in reality](#) – A one-page infographic produced by East London NHS Foundation Trust.
- [Q Liberating Structures user group](#) – Many Q members find Liberating Structures an inspiring way to enable more inclusive, innovative, productive (and fun) meetings and projects. This online user group offers an opportunity to learn how to use Liberating Structures with other people involved in improvement.
- [Creative approaches to problem solving: Methods toolkit](#) – Q’s toolkit of 25 tried-and-tested methods for creative collaboration and problem-solving.

“That element of co-production seems to really sit front and centre whether that’s... gaining and maintaining trust or whether that’s the need for services to reflect and meet the needs of people accessing them.”

Collaborating with and learning from others

Many participants are doing work that is new to them: they are trying to take a different approach and to engage different people. This presents both an opportunity and a challenge, and participants expressed different levels of comfort with this. We heard about feelings of uncertainty and vulnerability where there is a lack of expertise or knowledge. And some participants conveyed a sense of frustration that this uncertainty can make others fearful about making decisions about what to prioritise, or which areas of work to stop, or start.

We heard that a good remedy to this is to find allies. Although this can be difficult, it is important to seek out others who have faced similar challenges (and so might have some answers), and work together in new or expanded teams. To work well together, people need to acknowledge their own position and expand their networks to explore the experiences, expectations and assumptions of others. It is also important to learn and apply the skillsets of communicators, facilitators, and initiators of conversation and co-design.

Although our group of participants were self-selecting, the action learning set methodology identified an appetite for shared spaces to learn and reflect with others undertaking similar work. This challenge-focused but supportive learning environment was seen as important in facilitating productive reflection – including around assumptions and individual biases. One participant commented that it had helped with ‘rethinking and reformulating strategies’, another valued ‘the experience in the room – just different perspectives and different experiences’, while another appreciated ‘the openness and candour’ that was brought to the challenges faced. Given the complex challenges to progress outlined in this report and elsewhere, at Q we strongly believe there is a need to offer more such spaces across health and care. At the same time, we recognise (and participants often shared) the difficulty in protecting time for this type of space, and that the time available will depend on the organisational and individual context.

“To maximise collaboration... a team is more than the sum of their parts. Teams can quickly be formed, change in size and disappear... Uncertainty, job insecurity, add different levels (macro, micro and meso)... affecting the motivation of the individual.”

5

As well as these broader supportive spaces, some participants also wanted to draw on examples of good practice around the use of data to tackle waits and address inequalities from across the health and care system. They recognised that some of the challenges they faced might not be new, but often did not know where to go to access good practice.

Resources and tools on this theme

- Networks working in this area:
 - [Join Q](#) – A connected community working together to improve the safety and quality of health and care across the UK and Ireland.
 - [Join the Data Science for Health Equity network](#) – The network uses the Slack messaging app.
 - [Join the Shuri Network](#) – The first NHS and care network of women from minority ethnic groups working in digital health.
- Find out more about [Action learning](#).
- Good practice around data, access and inequalities (although there are only limited examples of where all three have been brought together).
 - FutureNHS, including the [Equality and Health Inequalities Network](#) (Those outside NHS England can join on request).
 - [The #SolvingTogether platform](#) – An approach to capture, assess and test learning and ideas that can support the priorities for health and care.
 - Recording of a Q event session on [Reducing waits and improving equity](#) – This includes two excellent examples of projects using data to make progress.
 - [Tackling inequalities in healthcare access, experience, and outcomes: Actionable insights](#) – This document aims to support NHS systems in reducing health care inequalities. It complements the Healthcare [Inequalities Improvement Dashboard](#) and [Actionable insights tool](#).

Conclusion

Record waiting lists and persistent inequalities in outcomes are causing significant harm across health and care. This project has reaffirmed existing calls for better quality data across the system. It has also generated insights on how less technical aspects of working with data are essential underpinnings of this work, including moving from data to action, the role of improvement, and the need for collaborative spaces and shared learning. Finally, the project has provided rich insights into the individual experiences of, and sometimes profound challenges faced by, those who are working in this messy area. These perspectives need to be more fully responded to if data practice is to match the ambitions and needs around access and inequalities.

Acknowledgements

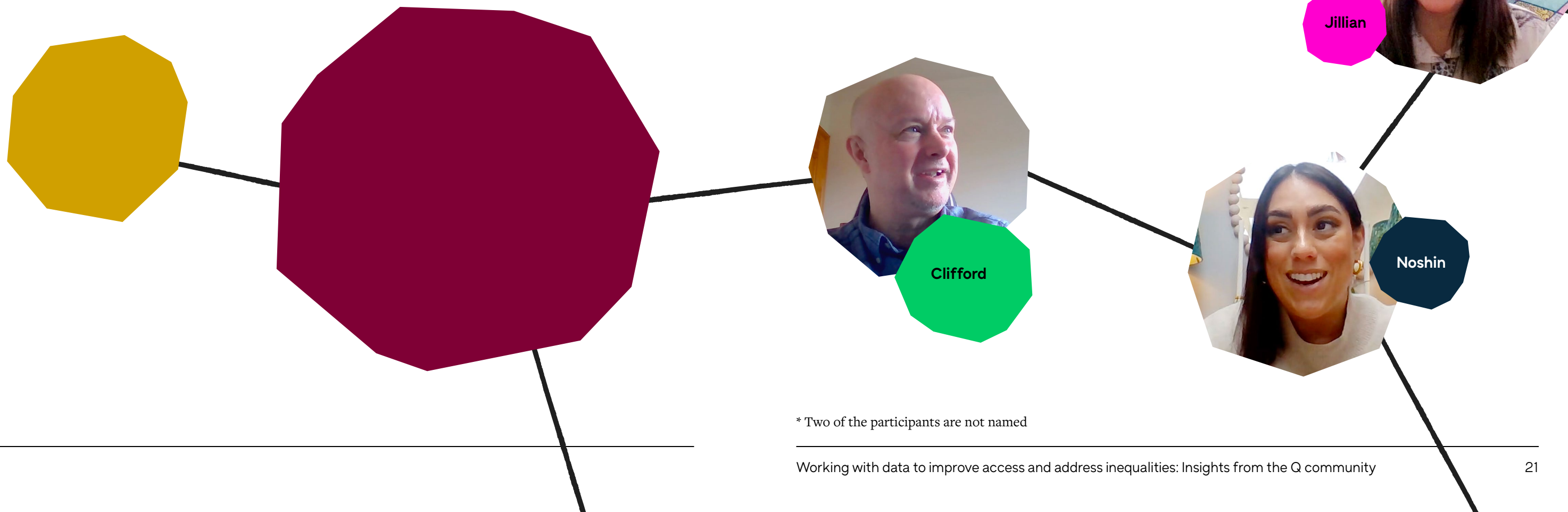
We are enormously grateful to all the participants in this project. They have generously shared open, honest and thoughtful insights to enable us to capture and take stock of the ups and downs of this work, despite having incredibly demanding workloads.

Thank you to the project participants: Nicola Ballingall, Sarit Carlebach, Ellen Coughlan, Edmund Glynn, Daniel Hardy, Noshin Menzies, Clifford Mitchell, Eithne Mullen, Jillian Owens, Chris Pavlakis, Jo Phillips, and Mai Stafford.*

Thank you to Clifford, Jillian and Noshin, who shared their experiences in video interviews. You can see what they said about being involved in the project and how they have applied what they learned on our website.

We also wish to acknowledge the expert facilitation provided by Fiona Scrase and Janie Wilson of the [Action Learning Centre](#), who created high-quality and supportive spaces for participants.

Thank you to internal reviewers, Penny Pereira, Gillian Connor and Melior Whitear, for providing invaluable comments on drafts of this report.



* Two of the participants are not named

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About Q

Q is a community of thousands of people across the UK and Ireland, collaborating to improve the safety and quality of health and care. We share our knowledge and support each other to tackle challenges. Together, we make faster progress to change health and care for the better. Through our insight work, we tap into the rich knowledge and diverse experiences of the Q community. We surface stories and generate and share actionable insight. This insight can be used by members and others across the health and care system to help them deliver improvement work more effectively.

Collaboration is at the heart of what we do. To ensure the greatest impact in our work, we aim to involve members at all stages and, where possible, collaborate with others working on the same topic. We use a variety of systematic methods to draw out the diverse experience and expertise of Q members relating to system priority areas. These include member surveys, workshops, case studies to amplify members' work, and ongoing share and learn projects. [Find out more about our insight work.](#)

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