GOOD PATIENT PARTNERSHIP GUIDE

2026

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IN PARTNERSHIP WITH OUR CONTRIBUTORS

Patient Journey Mapping With the Patient Community, Not For:

How advocacy partnerships create illuminating, credible, equitable, and actionable patient journey insight

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GOOD PATIENT PARTNERSHIP GUIDE 2026

Our panel of advocacy experts from the patient community and industry

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Patient journey mapping is now widely used across life sciences to inform decisions – from research priorities and clinical development to medical affairs planning, brand strategy, patient support and education. Yet our contributors emphasised a consistent truth: how a journey map is created matters as much as the output itself. If mapping is produced without meaningful partnership, it risks reinforcing bias, excluding under-represented voices, and capturing only the clinical pathway rather than the full lived experience.

This fourth edition of the Good Patient Partnership Guide (GPPG) explores patient journey mapping as a partnership-led insight discipline. Through a group discussion with patient organisations and advocates, and interviews with industry colleagues, we examined what 'good' looks like in practice: the practicalities of partnering, how to embed diversity, equity and inclusion by design, how to capture the multi-dimensional reality of living with a condition (including carers and family), and where artificial intelligence (AI) can responsibly support – but never replace – meaningful collaboration.

What we heard (in brief)

- **Language matters.** 'Journey' can feel linear, chosen and finite. Many contributors preferred 'experience', 'roadmap', 'life-with' or 'narrative' framing – with clear caveats that any map is a snapshot and never a single truth.
- **Partnership is not a bolt-on.** Credible journey mapping requires patients, carers and patient organisations to be involved early, with clarity on purpose, use and benefit – and with respect for each stakeholder's expertise.
- **Breadth beats tokenism.** One map cannot represent an entire population: inclusive mapping demands intentional outreach beyond the 'loudest' and most common voices, and often beyond a single patient organisation.
- **The lived experience is multilayered.** Traditional mapping often centres the clinical pathway, whereas the contributors urged mapping practical, emotional and social dimensions and the interconnected experience of carers and family.
- **Operational realities can make or break trust.** Contracting burden, timelines, feedback loops and how insights are shared back to communities shape whether partnerships feel trusted or tokenistic.
- **AI is a tool – not an author.** The contributors described opportunities for analysis, accessibility and translation, alongside risks of bias and 'hallucinations'. A consistent theme: transparency and human verification are essential.

Who this guide is for

This guide is designed for life sciences teams (medical, patient advocacy, R&D, brand, market access and communications) and patient organisations/independent advocates who collaborate on patient journey initiatives. It offers principles, practical guidance, quotes and examples to support repeatable, equitable partnership-led journey mapping.

Who we need to thank

The development of this Guide could not occur without all our contributors sharing their valuable time, effort, and perspectives. We sincerely appreciate their support, and trust you will find the output valuable.

All Patient Advocacy Contributors

Patient journey mapping is becoming a cornerstone of decision making in life sciences. As organisations increasingly use lived experience insights to shape strategy and investment decisions, there is growing recognition that journey mapping is only valuable when it is credible, actionable and rooted in reality – not just a clinical pathway or a single 'average' route.

Done well, it can illuminate unmet needs, highlight inequities in access and experience, and inspire more relevant solutions. Done poorly, it can reduce lived reality to a neat diagram, capturing only what is easiest to see and measure rather than what it is like to live with a condition day-to-day.

The contributors described a clear shift in the level of focus – and resourcing – being put behind patient centricity and the structured capture of patient experience. In some organisations, journey maps are being embedded into brand planning and used as a north star to connect initiatives to specific unmet needs. Elsewhere, teams are investing in practical methods to bring patient insights closer to the point of decision making, including advisory formats that test what people can actually find, understand and act on, and 'what now/what later' planning that separates immediate improvements from those requiring broader system or regulatory evolution.

With increased value being placed on lived experience comes increased responsibility. Journey mapping that is developed without meaningful partnership risks reinforcing bias, excluding under-represented voices and creating an incomplete picture that can inadvertently drive the wrong decisions. A journey map is always a snapshot, and it becomes more trustworthy when it is co-created with people with lived experience, their carers and families, and with patient organisations who can help reach diverse communities and interpret nuance across different lived realities.

Partnership is what enables credibility, depth and representation, and it is also what ensures the outputs can be used responsibly, shared appropriately, and ultimately contribute to better outcomes for patients and families.

In this section, we explore the themes that emerged most strongly across the contributor discussions.

Reframing 'the patient journey': terminology, caveats and context

The phrase 'patient journey' is widely used in industry, yet it can jar with those with lived experience. The contributors described these journeys as non-linear, often without a clear endpoint, and not something a person chooses. Many preferred language that reflects reality: experience, roadmap, narrative or 'life-with' mapping. Even those comfortable with 'journey' stressed the need for clear caveats: any map is a snapshot, not a universal truth.

Trudie Lobban MBE
Founder and Trustee,
Arrhythmia Alliance

"Journeys are usually something you choose and plan to be linear. When you are ill, you are dragged down pathways you never planned and often encounter lots of wrong turns and reversing. **It is less of a journey and more of an experience; a web or tapestry of lived experience with a condition.**"

Trishna Bharadia MFPM (Hon)
Patient Engagement Consultant and
Health Advocate, The Spark Global

"**One map doesn't represent an entire patient population.** The language around it needs to evolve to imply the capture of the diverse experience of those with lived experience of a disease."

Luke Langlands
Chief Executive Officer,
Tuberous Sclerosis Association

"Patient roadmap language can work to suggest a breadth of experience, but we need to be mindful that whatever terminology we use, the output does indeed capture a wealth of different experiences. **Just because someone has a loud voice doesn't mean it represents the most typical experience – we must include all voices.**"

Will Woan
Executive Director,
Heart Valve Voice

"There can be confusion between a patient pathway, journey and experience. **Any patient journey mapping should encompass the lived experience; medical, physical, practical and emotional, and should avoid connotations of optimal and sub-optimal.** Terminology needs to provide clarity regarding what is being mapped."

Steve Clark
Patient Engagement Consultant,
Pharma Management Consultant
and Patient Advocate, and
Founder of Strive for Five

"I don't object to the phrase 'journey'... so long as it comes with caveats such as an asterisk to say this is an example – a snapshot to draw from – **individual experiences will vary hugely.**"

Emma Collins
Patient and Public Involvement
Research Manager,
Encephalitis International

"We tend to talk about living with the effects rather than a journey, because **experiences change over time and don't follow a straight line... 'patient journey' can be used, but carefully.**"

Championing partnership-led journey mapping

The contributors repeatedly described partnership as the differentiator between a credible, actionable map and a tokenistic exercise. Partnership was framed as a relationship built on transparency, respect and shared purpose rather than a one-off transaction. A consistent message was that patients and patient organisations should be involved from the beginning: shaping the questions, the method and the interpretation, not simply validating a near-final output.

Trudie Lobban MBE
Founder and Trustee, Arrhythmia Alliance

"Consider a jigsaw – you need all the pieces. Here, you need 3 pieces: industry, people with lived experience/patient organisations, plus healthcare professionals to create a complete experience picture. **Respect each other's skills, work together, and the output will be far better.**"

Ann Fish-Steagall
BSN, RN, Senior Vice President of Patient Services, LUNGevity

"**Patient and patient community comes first** – the journey map project must be for the benefit of the patient community and must involve those with lived experience from the outset, ie, in the planning stage not just the research stage."

Trishna Bharadia MFPM (Hon)
Patient Engagement Consultant and Health Advocate, The Spark Global

"We must be willing to have long-term relationships with the patient community and patient advocacy groups (PAGs) and we have to regularly re-visit the patient journey, evolve and update it to reflect changes in guidelines, treatment availability, and societal and economic changes. **Patient journey maps should be dynamic and there should be a commitment to do this when embarking.**"

Mark Sterckel
Patient Engagement and Artificial Intelligence Expert Consultant

"Too often findings remain internal and this gives rise to a missed opportunity. **In a true partnership, the final output and findings should be shared with the patient community to enable contributors to realise the value of their participation** and to allow patient organisations to leverage the findings for their own activities."

Making collaboration practical, repeatable and scalable

Even with strong intent, operational friction can undermine partnerships. The contributors highlighted common barriers: complex contracting, unclear expectations, limited resources, and inconsistent funding and follow-up. They also shared practical approaches that make journey mapping repeatable: clear planning, cross-functional involvement, and methods that combine breadth (surveying or wider input) with depth (qualitative exploration and validation).

Mark Sterckel
Patient Engagement and Artificial Intelligence Expert Consultant

"Contracting can be a disaster and can include a lot of pages of complicated text that is a challenge for PAGs or individuals with lived experience to understand. **We must focus on simplifying** the contractual process to avoid time delays, frustrations and dropouts before you even get to the stage of input. Bringing in finance, medical and legal teams at the outset can help simplify and streamline processes."

Megann Looker
Exec. Director, Head of Global Product Labelling, Jazz Pharmaceuticals

"**We must be careful to avoid participant fatigue.** If, across industry, we collaborate frequently with people with lived experience, they can easily tire of communicating the same things and never really seeing any change. We should consider what we can do to avoid research and participation duplications, and clearly communicate to participants what change, based on lived experience, can be actioned now versus later."

Steve Clark
Patient Engagement Consultant, Pharma Management Consultant and Patient Advocate, and Founder of Strive for Five

"**Ensuring funding for patient journey mapping or other research activities can be difficult when there are personnel changes.** This can lead to funding getting pulled, or support for an initiative waning. Key principles should be adhered to: talk together across the pharma company, enable links in the chain to new personnel, collaborate (or set up if not in existence) patient engagement departments that can influence the practicalities of partnerships and encourage best practice."

Luke Langlands
Chief Executive Officer, Tuberous Sclerosis Association

"The value of lived experience involvement must be recognised via appropriate remuneration. It must be considered and agreed upon early, alongside payment terms, and **agreements must be adhered to**. Getting this right supports PAGs and individual advocates with lived experience to collaborate on current initiatives and encourages repeat future involvement."

Meaghan Krohe
Director, Patient Insights & Solutions, Astellas

"We engaged [the patient advocacy groups] early in the research process. They reviewed the concept, provided feedback on the survey questions, and were **involved at several touch points throughout the research to ensure continued alignment.**"

Embedding diversity, equity and inclusion by design

The contributors were clear: representation does not happen by accident. A single patient organisation, a single advisory board or a small set of willing volunteers cannot capture the breadth of lived experience – particularly where geography, ethnicity, sex, gender, socio-economic background, literacy, language and comorbidities shape care pathways. This challenge is amplified at a global level, where reliance on the most visible or established organisations risks reinforcing existing gaps. The contributors, therefore, urged **intentional design**: multiple routes to participation, proactive outreach to under-represented communities, and transparency about the limitations of any single approach.

Will Woan
Executive Director,
Heart Valve Voice

"**Depending on where you live, your gender, ethnicity and many other aspects, your lived experience of a condition will be different.** We need to close the gaps and differences that exist, and to do this we need to understand them and realise who is receiving optional or sub-optimal care. To understand this, we need to be very careful to ensure research represents as diverse a population as possible."

Trishna Bharadia MFPM (Hon)
Patient Engagement Consultant and
Health Advocate, The Spark Global

"Collaborating with one patient group may not be enough – **collaborate with many to help you consider multiple channels of outreach, a diverse patient community**, varying literacy levels, the postcode lottery of specialist centre locations and the intersectionality of not just patient demographics, but how they link into having a healthcare system."

Luke Langlands
Chief Executive Officer,
Tuberous Sclerosis Association

"Any PAG worth its salt should have very clear equity, diversity and inclusion (EDI) policies for public and patient engagement. I can't tell you the lived experience myself, but I can tell you a broad experience based on conversations with 1000s of patients over 10 years. **It is up to industry as well as PAGs to ensure the diverse patient voice and broad representation is there.**"

Emma Collins
Patient and Public Involvement Research Manager, Encephalitis International

"People can become experts at taking part in research...research can often recruit those willing and this gives rise to a bias in the type of people involved. We need to guard against this where possible and **seek input from people that may not be typically forthcoming about sharing their experiences.**"

Megann Looker
Exec. Director, Head of Global Product Labelling, Jazz Pharmaceuticals

"**Certain types of people are predisposed to volunteering** and cultural tendencies can impact this, so there is inherent bias and limitations no matter how hard we try to avoid them. We need to acknowledge this but also not let it stand in the way of doing the best we can to understand the lived experience."

Trudie Lobban MBE
Founder and Trustee, Arrhythmia Alliance

"It is not necessarily industry or anyone's fault that patient voices are missed – **sometimes recruiting a diverse research pool is a huge challenge.** Whatever support materials are developed because of insights gathered should be co-created with the patient community, translated and accessible – pharma can support this by funding PAGs to do it."

Capturing the full lived experience: beyond the clinical pathway

A recurring theme was that mapping often focuses on the clinical pathway – appointments, tests, treatments – while missing the practical, emotional and social realities that influence outcomes and quality of life. The contributors described the importance of capturing comorbidities, the evolution of experience over time, and the role of carers, family and support networks. Several also highlighted that the same words can mean very different things to different stakeholders, underscoring the need to co-create language and interpretation.

Trudie Lobban MBE
Founder and Trustee,
Arrhythmia Alliance

"Most mapping has been done by doctors...they tend to map the clinical journey, not the lived experience. The more all-encompassing a patient journey map can be, highlighting practical, clinical, physical and emotional aspects of lived experience the better. We need to ensure we are truly capturing lived experience, for example, **a patient experience of safety may be very different to a doctor's.**"

Mark Sterckel
Patient Engagement and Artificial Intelligence Expert Consultant

"**It is important to involve carers, partners and family, and vital to involve the nurses** to gather insights from a range of people and consider varying perspectives. A patient journey map must be as full and broad as possible."

Emma Collins
Patient and Public Involvement Research Manager, Encephalitis International

"**Individual lived experience of a condition and the lived experience of their families and healthcare professionals is so interconnected**. We must try to harness it all in patient journey mapping."

Trishna Bharadia MFPM (Hon)
Patient Engagement Consultant and Health Advocate, The Spark Global

"Within each phase of a patient journey we must try to explore what is needed emotionally, physically, informationally, supportively, and medically. **At each stage of the journey, we must ask what do the insights mean**, what does the patient need, what more could we do to support?"

Ann Fish-Steagall
BSN, RN, Senior Vice President of Patient Services, LUNGevity

Trishna Bharadia MFPM (Hon)
Patient Engagement Consultant and Health Advocate, The Spark Global

"Journeys change: science evolves, guidelines shift, new treatments emerge, and health systems change. **Journey maps should, therefore, be treated as an evolving living insight** – revisited, re-validated and refreshed over time as the reality of lived experience changes."

Kat Bernacki
Director, Patient Insights & Solutions, Astellas

Meaghan Krohe
Director, Patient Insights & Solutions, Astellas

"If you only map the clinical steps, you miss what actually shapes behaviour. The emotional highs and lows, **the moments of uncertainty, and where people disengage are just as important as the pathway itself** – that's where the real opportunities to support patients sit."

Key Do's and Don'ts for Partnership-led Patient Journey Mapping

This short list consolidates practical guidance that the contributors emphasised repeatedly. It is designed to be a quick reference for teams planning or running journey mapping initiatives.

Do:

- **Embed partnership from the start.**
  Involve people with lived experience and patient organisations as part of the core project team *before* objectives, methods, contracting, budgets and outputs are fixed. Where possible, embed a patient advocate in the design phase to shape direction and decision making from the outset.
- **Do your landscape mapping first.**
  Conduct thorough landscape mapping in partnership with patient advocates *before* insights collection to identify sub-groups within the patient population, potential biases, and appropriate channels – particularly to reach under-represented communities.
- **Design for representation, not convenience.**
  Recruit intentionally, use multiple channels and formats, and consider working with more than one community or advocacy partner. Patient advocates can open channels others cannot and help create safer, more comfortable spaces for participation.
- **Combine breadth with depth.**
  Use methods that capture wide input (for example, surveys or broader listening) alongside qualitative exploration and validation, supported by patient advocates who can help interpret nuance and context.
- **Focus on moments that matter.**
  Prioritise critical touchpoints that have the greatest impact on patient experience, satisfaction and outcomes – not just the most visible or easily mapped stages.
- **Map the whole lived experience.**
  Go beyond the clinical pathway to include practical, emotional and social dimensions, and the experience of carers and families where relevant. Recognise that experiences are non linear and not lived in isolation.

Do:

- **Sense check continuously.**
  Regularly return to patient advocates and participants to test assumptions, language and interpretation – small course corrections often prevent major misalignment later.
- **Validate, iterate and update.**
  Treat journey maps as living artefacts. Revisit and evolve them as science, systems, language and lived experience change, rather than allowing them to become static outputs.
- **Close the loop visibly.**
  Share outputs back with participants and communities, explain decisions and next steps, thank contributors, and be clear about how and when the journey will be refreshed.
- **Be transparent about limitations.**
  Clearly state what a journey does, and does not, represent, and avoid presenting any map as *the* patient experience.

Don't:

- **Treat journey mapping as a tick-box deliverable** or something that 'goes in a drawer'.
- **Assume one map represents everyone** or present a single pathway as the universal truth.
- **Rely only on the 'usual volunteers'** or the loudest voices. This risks reinforcing existing bias.
- **Skip landscape mapping** and default to the most visible or convenient patient channels.
- **Over-burden partners** with complex contracting, unclear timelines or last-minute requests.
- **Correct or challenge participants in the moment.** Participants may hold opinions or inaccuracies – listen first, seek to understand context, and question gently.
- **Ignore language and terminology.** Don't assume industry-standard language works for patients; failing to ask can undermine trust far beyond the mapping exercise.
- **Use AI as a substitute for lived experience** or rely on opaque AI-generated outputs without human verification.

Best Practice Examples (Case Studies)

The examples that follow reflect approaches the contributors described during interviews that we hope offer inspiration for future patient journey mapping activities.

Pancreatic cancer emotional journey map & community dissemination – *Astellas*

A pancreatic cancer emotional journey map was presented at the 2025 PanCAN Scientific Summit, and subsequently shared with the wider community.

- **The challenge/need:** Ensure the journey reflected not just clinical touchpoints but the lived emotional experience and 'moments that matter'.
- **Partnership model:** Worked with an advocacy community/summit setting to share and discuss insights externally.
- **Methodology and approach:** Qualitative approaches used with key groups (patients/caregivers/care teams/advocacy input) in journey mapping work.
- **Outputs:** Emotional journey map; presentation at advocacy summit; subsequent broader community presentations/sharing.
- **Impact/Insights:** External sharing reinforces credibility, invites accountability, and helps ensure the output is useful and resonant to the community.

Menopause research and infographics hosted by an advocacy group – *Astellas*

Research outputs from a menopause study that were published in Preventative Medicine Reports were translated into patient-friendly infographics and shared via an advocacy group' newsletter to their community.

- **The challenge/need:** Convert research insights into formats that better supported patient understanding and real-world usability.
- **Partnership model:** Advocacy group created materials and disseminated; outputs shared via social media and newsletters to community
- **Methodology and approach:** Research/journey insight work, including surveys and qualitative feedback.
- **Outputs:** Research findings were first presented at two leading medical conferences (ACOG and NPWH), subsequently published in a peer-reviewed scientific journal, and then translated into patient-friendly infographics hosted on the advocacy organisation's website.
- **Impact/Insights:** Demonstrates 'insight→action': transforms evidence into practical patient resources; reinforces the Guide's principle of co-created, actionable outputs.

Structured journey innovation through cross-company collaboration – *Mark Sterckel*

A multi-company, workshop-led approach to patient journey innovation, referenced through industry examples including *The Synergist* campaign and a fertility journey initiative (*Ferring Fertility*). The model centred on an intensive three-day 'journey innovation' structure, designed to move teams from shared understanding to prioritised, implementable solutions.

- **The challenge/need:** Reframe patient journey mapping as an active innovation discipline, not a static insight output.
- **Partnership model:** Cross-functional industry participation to build shared understanding and internal buy-in; designed to bring patients and carers into the process, particularly at the ideation and decision-making stage rather than limiting their involvement to research inputs.
- **Methodology and approach:** A clear, repeatable three-day structure:
  - Day one, foundations: build shared understanding of the journey, align on context, constraints and objectives
  - Day two, insight generation: conduct interviews, consolidate insights, then cluster and theme to identify key needs and opportunities
  - Day three, innovation and prioritisation: structured ideation against identified needs, with solutions prioritised based on feasibility alongside ambition (wow factor). Where possible, patients and carers brought into this stage to contribute to and vote on priorities
- **Outputs:** An Interactive map enabled via collaboration across organisations and teams, rather than asset or silo-led journey work.
- **Impact/Insights:** Creates an organisation-wide understanding of the patient journey; prioritises solution concepts grounded in patient insight and practical constraints; gives clear direction for implementation, rather than insight left at a conceptual level.

Bringing together patient organizations from different disease areas to map comorbidities – *Boehringer Ingelheim*

A partnership-led patient journey mapping approach used to identify high-impact intervention points and translate them into funded, patient-facing advocacy campaigns.

- **The challenge/need:** Patients' lived experiences often span multiple conditions and care pathways, meaning critical risks and opportunities are missed when journeys are viewed in isolation or mapped too narrowly.
- **Partnership model:** Collaboration with patient organisations to identify opportunities to better diagnose and treat people with multiple connected conditions; supported via a grant to fund a connected care program for patients with cardio-renal-metabolic (CRM) disorders.
- **Methodology and approach:** Patient journey mapping used to identify 'moments for impact' across the disease continuum.
- **Outputs:** Identified a critical moment linking kidney disease and heart disease, two interconnected conditions often managed separately; led to funding a 6-month national campaign to empower patients to request both checks during routine GP visits.
- **Impact/Insights:** By bringing together patient organisations from different disease areas, we can identify where diseases intersect and opportunities for early diagnoses. In this case, when heart failure patients should advocate for screening for associated, asymptomatic diseases.

From patient journey insight to advocacy action: identifying moments for impact – *Boehringer Ingelheim*

Patient journey mapping helps patient organisations with limited resources identify moments of impact – where their advocacy could have the greatest impact.

- **The challenge/need:** Patient organisations gathered at the Boehringer Global Patient Partnership Summit (GPPS) and asked for a methodology to map patient symptoms.
- **Partnership model:** Boehringer commissioned Patvocates, a patient-led social consultancy, to develop a free, publicly available Patient Pathway Toolkit – with input from the GPPS Patient Steering Committee.
- **Methodology and approach:** The toolkit helps visualise real-world challenges across the care continuum — from prevention and diagnosis to treatment and long-term care. The template is disease agnostic – in recognition that while various stages of a disease pathway can look different to others, there are also a lot of commonalities – and adaptable.
- **Outputs:** The toolkit provides a practical and customisable methodology to map care progression, identify barriers, and build more targeted, effective advocacy responses. It is hosted by the European Patient Advocacy Institute (EPAI) and freely accessible under the Creative Commons licence.
- **Impact/Insights:** The toolkit was piloted in pulmonary fibrosis and colorectal cancer and has been used by Boehringer, with HCPs and rare cancer patient groups, to identify high impact opportunities for R&D and pathway redesign.

Evaluating the impact of co-produced resources – *PIF*

St Mark's inflammatory bowel disease (IBD) service was the pilot site for PIF's Perfect Patient Information Journey (PPIJ) project between 2017-2022.

- **The challenge/need:** Patient journey mapping revealed the need for more information at point of diagnosis and during flare-ups, and the relatively low awareness of the information provided by the Crohn's & Colitis UK charity.
- **Partnership model:** The next phase took the recommendations from insight work with patients and the IBD team and implemented them as part of a quality improvement programme.
- **Outputs:** A new diagnosis clinic was established, a flare card was created and digital signposts were added to Crohn's & Colitis UK's specific information pages.
- **Impact/Insights:** The project is an example of cross-sector collaborative working – NHS England provided patient activation measures to measure the impact of a new diagnosis clinic (for non-activated patients, around 6 in 10 showed an improvement); Crohn's & Colitis UK supplied content and bespoke tracking links to its information; PIF provided expert guidance throughout the project cycle and AbbVie provided funding.

Tackling inequalities in maternity care – *PIF*

The aim was to co-produce culturally appropriate, translated maternity resources tailored to meet the needs of the highest-risk service users and those facing digital exclusion using the Perfect Patient Information Journey (PPIJ) process.

- **The challenge/need:** Black and Asian women experience the poorest maternity outcomes of all population groups nationally, particularly if they are also experiencing deprivation. In 2024, PIF worked with Women's Health Sussex, Trust for Developing Communities (TDC) and Rivers LPC to produce resources designed to tackle these inequalities.
- **Methodology and approach:** Engagement with women from diverse backgrounds, including an in-person event with interpretation.
- **Outputs:** An illustrated timeline of key points on the maternity journey; 5 easy-read guides; 5 short videos which could be shared on social media and via WhatsApp. All resources were translated into the 10 languages most frequently spoken by Sussex maternity service users.
- **Impact/Insights:** In 2025, another trust asked to use the resources to help tackle inequalities in their area. PIF is working on two further projects to tackle health inequalities in maternity care. The first focuses on mental health and the second sexual health.

TSC and Me – *TSA*

A conscious effort to broaden the diversity of the Tuberous Sclerosis Complex community as reached by the Tuberous Sclerosis Association. Through social media, the many different lives and experiences of people affected by TSC were celebrated, highlighting different backgrounds so that those from minority groups feel more at ease contacting the TSA for support.

- **The challenge/need:** To broaden the range and diversity of people engaging with TSA and ensure it wasn't heavily biased towards White British groups of people.
- **Methodology and approach:** Develop and disseminate social media content reflecting a diverse population to encourage people from all backgrounds and experiences to engage with TSA and potentially take part in research, including journey mapping.
- **Outputs:** Stories from people living with or caring for someone with tuberous sclerosis that highlight diversity; varying experiences to powerfully shed light on the reality of living with the condition.
- **Impact/Insights:** The range of the content led to an increase in the diversity of people getting in touch and collaborating with TSA, paving the way for inclusive and representative research and journey mapping possibilities.

Staged interactive journey map – *LUNGevity*

LUNGevity has entered into an industry-sponsored project designed by LUNGevity and a graphics design company. It aims to deliver an interactive journey map by stage.

- **The challenge/need:** To create a holistic and in-depth picture of the experience of the patient with experience of those with non-small cell lung cancer (NSCLC) in all its richness but also offers added value to the viewer/user.
- **Partnership model:** A joint initiative with a co-created deliverable.
- **Methodology and approach:** First step was to identify the common questions, challenges and information needs of patients, care partners and survivors at each stage of NSCLC, from those awaiting diagnosis through to those newly diagnosed and navigating treatment. These insights were informed by interviews with multidisciplinary experts across pulmonology, medical oncology, thoracic surgery, advanced practice nursing and radiation oncology. Expert perspectives were then edited into short, accessible video soundbites and embedded within the relevant stages of the journey map, enabling users to access targeted information at the point most relevant to their individual experience, rather than needing to absorb the full NSCLC pathway at once.
- **Outputs:** A visual and interactive journey map covering all things related to each stage of NSCLC from stage I-IV soon to be available on the LUNGevity website. It includes definitions, graphics and links to resources. In addition, each stage has links to expert videos from KOLs speaking about all aspects of work-up and treatment to side effect management.
- **Impact/Insights:** The project could not have been accomplished without the volunteer efforts of the KOLs and the generous sponsorship of industry. The final map will greatly benefit the patient and medical community and enable great understanding of the condition. LUNGevity is in the process of raising funds to replicate this for SCLC and to enable embarking on phase II of the project, which will include development and provision of more general information on health and wellbeing at each stage.

Focus on the Future: Where Journey Mapping Goes Next and the Role of AI

The contributors were optimistic about how patient journey mapping could evolve, in particular in relation to sharing learning without losing trust, and harnessing the power of AI.

They discussed the aspiration to reduce duplication by sharing journey learnings more broadly across the life sciences sector, but noted that governance, roles and funding can make this difficult. A realistic near-term step may be to share principles, methods and anonymised insights more openly, and to create feedback loops that allow communities to benefit from what they helped build.

The impact of maturing digital tools and AI was explored, and the contributors were positive they could bring benefit but were cautious about risks. The consistent message was 'high tech and high touch': use digital tools and AI to augment, improve accessibility and efficiency, but retain human judgement, transparency and partnership to keep lived experience at the centre.

Where AI could responsibly support

- Synthesising large volumes of qualitative input to identify patterns, themes and unmet needs – with human review to retain nuance.
- Improving accessibility (eg, translation, alternative formats) and reducing practical barriers to participation.
- Creating interactive, personalised ways to explore journeys (eg, different profiles/personas), helping teams avoid a single 'one-size' map.

Risks the contributors highlighted

- Bias: AI can amplify the biases in its training data and in what it is asked to prioritise.
- Hallucinations and accuracy: in regulated contexts, errors can be harmful – verification is essential.
- Loss of emotion and context: over-automation can strip away the 'kitchen-table' insight that comes from human conversation.

Mark Sterckel
Patient Engagement and Artificial Intelligence Expert Consultant

"There is no 100% safe AI. Every time you put the same prompt into a different AI tool you get a different answer. **AI can help for sure, but the human input is always required.**"

Emma Collins
Patient and Public Involvement Research Manager, Encephalitis International

"There could be a role for AI to support with translation of materials and/or simultaneous translation during research interviews. However, **it brings potential challenges with it**: hesitancy over patients getting involved/inaccuracies in translation/limitation to the research validity."

Megann Looker
Exec. Director, Head of Global Product Labelling, Jazz Pharmaceuticals

"Anything generated by AI should have a badge on it: **'Generated by AI, verified by humans'.**"

Close

Partnership-led patient journey mapping is not a single activity; it is a way of working. When life sciences teams and patient communities co-create journeys with intention – designing for representation, mapping the full lived experience, and translating insight into action – journey mapping becomes more than a diagram – it becomes a catalyst for better decisions and more equitable outcomes.

We hope the reflections, quotes and examples in this guide support you to strengthen how you partner, how you map, and how you use insights. If you would like to explore any of the approaches further, please contact the Precision AQ Patient Engagement team.

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Acknowledgements

With thanks to all contributors who shared their time, expertise and lived experience to inform this guide.