

Scottish Cancer Patient Reported Outcome Measures Forum

KEY LEARNING & RECOMMENDATIONS FROM
MEETING 3 - 1ST DECEMBER 2023

The 3rd SC PROMs Forum event 1st Dec 2023

The online event featured a comprehensive agenda with 6 speakers including academics, healthcare professionals and those working with PROMs in research and clinical practice. A total of 110 people registered and 70 attended. The Scottish Cancer PROMs Advisory Group, with help from previous Forum events, developed a set of PROMs Core Principles, which were approved by Scottish Government in August 2023. The aim of the Dec event was to share the Core Principles and discuss how we can best encourage their uptake in Scottish clinical practice through a series of workshops (“breakouts”).

On the next pages you will find a *summary of the PROMs Core Principles, the event agenda, our key messages from the breakouts, our recommendations from the event and plans moving forward.* You will then find *biographies of each speaker* and details of how to get *more information on the Scottish Cancer PROMs Forum and Advisory Group.*

The Scottish Cancer PROMs Forum (SC PROMs Forum) is an open collaborative space for anyone to contribute and learn from current and future work in Patient Reported Outcome Measures (PROMs) and how they can be collected as part of routine care to better understand and manage the impact that cancer treatments have on quality of life. The Forum will support the Advisory Group in developing a set of key principles for the collection and use of PROMs in clinical practice in Scotland.

Many thanks to the speakers and breakout facilitators who contributed to the event, all of the attendees who participated and posed questions and comments, the Executive Team for organising and facilitating the event, and the SC PROMs Advisory Group for their steer and support.

Summary of the PROMs Core Principles



Set Out a Plan for the Evaluation of PROMs

It's important to track how PROMs projects are doing over time, so that they can be improved.



Ensure Planning and Resource Allocation for Adoption & Implementation

Teams need to ensure they have the finances, staffing and equipment needed to collect PROMs as part of routine care.



Develop a Governance Framework

Any existing laws, policies or regulations should be followed, and there needs to be a clear outline of how PROMs data is collected, stored and protected.



Have Active Stakeholder Engagement & Cooperation

The people who will be impacted by the collection and use of PROMs need to be consulted on how this should happen.



Have Clearly Defined Outcome Measures

People designing/adopting PROMs need to have a clear idea of what exactly they want the PROMs to measure (e.g. severity side effects).



Use Valid and Consistent PROMs tool(s) / Items

There are lots of different tools (like questionnaires) out there for collecting PROMs. Tools or questions within tools that are of a high quality should be used.



Take an Integrated Approach to PROMs

Collecting PROMs should work in harmony with any digital systems used, with the ways that clinical teams work, and within the care pathway that patients may be on.



PROMs should be completed by patients / with carers

Self-explanatory. The patient voice is most important in PROMs.



Analyse, Interpret, Report, & Disseminate PROMs Data

It's not enough to collect PROMs data from patients. Clinical teams need to look at the information patients provide as part of patient care, and do something with that information.



Consider Accessibility / Inclusivity

Patients who want to complete PROMs should not be limited by language or any impairment, for example. Also, any patients who choose not to complete PROMs should not be disadvantaged in any way.

Scottish Cancer PROMs Forum Meeting 3 Agenda

Friday 1st Dec 2023 10am – 12:30pm, MS Teams Webinar

INTRODUCTION		CHAIR: PETER HALL
Welcome from Scottish Cancer Patient Reported Outcome Measures Advisory Group (SC-PROMs AG) and introduction to the SC-PROMs Forum	10:00am–10:05am (5 mins)	Emma Dunlop (Research Associate, Cancer Medicines Outcomes Programme (CMOP) University of Strathclyde, Co-Chair of the SC-PROMs AG)
Presentation from the MyPath PROMs project team <i>Questions</i>	10:05am–10:20am (15 mins)	Dr Kathrin Cresswell (Senior Lecturer) Prof Robin Williams (Director - ISSTI), University of Edinburgh & Dr Peter Hall (Reader and Consultant Medical Oncologist, Edinburgh Cancer Research Centre, University of Edinburgh; Edinburgh Health Economics Group Lead, Edinburgh Clinical Trials Unit & Co-Chair of the SC PROMs AG)
Introduction to PROMs Core Principles <ul style="list-style-type: none"> • What are the Scottish Cancer PROMs Core Principles? • How were they developed? • Progress so far 	10:20am-10:30am (10 mins)	Emma Dunlop (Co-Chair SC PROMs AG / Researcher for Cancer Medicines Outcomes Programme (CMOP), University of Strathclyde), Debbie Provan (Cancer & Rehabilitation Unit, Scottish Government) & Anne Leitch (Value Based Healthcare Programme Lead)
Session 1 Breakouts Breakouts will run at the same time and are focused on Core Principles that may be of more interest to patients, patients and clinicians, and innovators and decision makers (see next few pages).	10:30am–10:50am (20 mins)	<i>Breakouts will be supported by a facilitator and are interactive- you can speak as well as provide comments using the Chat. Please read the Participation guide provided nearer the time.</i>
BREAK	(10 mins)	
Session 2 Breakouts Breakouts will run at the same time and are focused on Core Principles that may be of more interest to patients, patients and clinicians, and innovators and decision makers (see next few pages).	11:00am–11:20am (20 mins)	<i>Breakouts will be supported by a facilitator and are interactive- you can speak as well as provide comments using the Chat. Please read the Participation guide provided nearer the time.</i>
BREAK	(10 mins)	
Session 3 Breakouts Breakouts will run at the same time and are focused on Core Principles that may be of more interest to patients, patients and clinicians, and innovators and decision makers (see next few pages).	11:30am-11:50am (20 mins)	<i>Breakouts will be supported by a facilitator and are interactive- you can speak as well as provide comments using the Chat. Please read the Participation guide provided nearer the time.</i>
DISCUSSION		
Discussion of what has been shared in workshops and group discussion of Core Principle 1: Evaluation	11:50am–12:20pm (30 mins)	Peter Hall
What next, and thank you	12:20pm-12:30pm (10 mins)	Scottish Cancer PROMs Advisory Group Executive Team
CLOSE		

Breakout Descriptions and Target Audiences

When you register you'll be asked to select which breakouts you would prefer to take part in. Anyone can attend any breakout, but some may be of more interest to:



patients/the public















clinicians






innovators (e.g. digital companies) & decision makers (e.g. managers or policy makers)

The breakouts will help us work out how to improve the uptake of the Core Principles, and also help predict any potential problems or risks. **Please read the descriptions and target audience information for Session 1, 2 and 3 below to help you choose which breakouts might be best for you.**

SESSION 1 BREAKOUTS		
1A	1B	1C
<p>Active Stakeholder (Patients/Public) Engagement & Cooperation</p> <p>We will introduce this Core Principle and share thoughts on effective ways to engage patients and their families in the collection and use of PROMs in routine care.</p>  	<p>Active Stakeholder (Clinicians) Engagement & Cooperation</p> <p>We will introduce this Core Principle and share thoughts on effective ways to engage clinicians in the collection and use of PROMs in routine care.</p>  	<p>Use of Valid and Consistent PROMs tool(s) / Items</p> <p>We will introduce this Core Principle and share thoughts on how to best choose the most valid and consistent PROMs tools.</p>  
	<p>Clearly Defined Outcome Measures</p> <p>We will introduce this Core Principle and share thoughts on choosing and clearly defining the outcome measures of most interest and importance.</p>  	

SESSION 2 BREAKOUTS		
2A	2B	2C
<p>PROMs to be completed by patients / with carers</p> <p>We will introduce this Core Principle and share thoughts on how to best ensure that patients are the ones completing PROMs (not clinicians on their behalf), as well as how carers can be included in the process.</p> 	<p>Planning and Resource Allocation for PROMs Adoption & Implementation</p> <p>We will introduce this Core Principle and share thoughts on how clinical teams but also innovators and decision makers can best plan for the collection and use of PROMs in clinical practice.</p> 	<p>An Integrated Approach to PROMs (Digital Integration)</p> <p>We will introduce this Core Principle and share thoughts on how we ensure PROMs collected is integrated into existing and future NHS and data systems.</p> 
	<p>An Integrated Approach to PROMs (Clinical Pathway Integration)</p> <p>We will introduce this Core Principle and share thoughts on how we ensure PROMs collected is integrated into clinical care pathways and ways of working.</p> 	

SESSION 3 BREAKOUTS		
3A	3B	3C
<p>Consider Accessibility / Inclusivity</p> <p>We will introduce this Core Principle and share thoughts on how to we ensure PROMs are accessible and inclusive to all different people and their needs.</p> 	<p>Analyse, Interpret, Report, & Disseminate PROMs Data</p> <p>We will introduce this Core Principle and share thoughts on how to PROMs data should be analysed, interpreted and shared with patients and clinicians.</p> 	<p>Develop a Governance Framework</p> <p>We will introduce this Core Principle and share thoughts on how to ensure PROMs adoption is compliant with existing policies and guidelines.</p> 

What did we discuss in the breakouts?

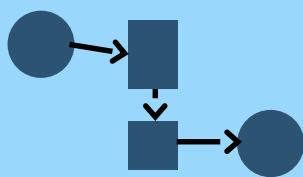
Although each core principle was discussed in each workshop, some themes overlapped across multiple principles. Therefore, the notes from the workshops have been taken and amalgamated, and fall under 4 main headings:



The People



The PROMs and the Purpose



The Pathways and Processes



The Unintended Problems

The People



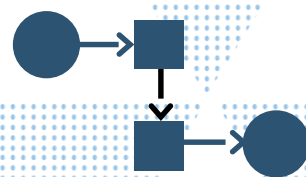
- It was recognised that it was the clinician’s responsibility to ensure that PROMs are collected and used, not the patient’s.
- Strong clinical and institutional / organizational leadership for PROMs adoption is required.
- Patients may need support in providing PROMs, either from staff (such as nurses or support workers) or family.
- Various staff members were mentioned who could view PROMs data, including nurses and the wider multidisciplinary team.
- It was acknowledged that clinicians are very busy, and so PROMs need to be compatible with the already high workload.
- Communication and collaboration between staff and patients, as well as PROMs adopters learning from one another, is necessary to ensure the right PROMs are collected by the right people and for the right reasons.
- Staff training in things like communication and consultation styles may be needed, not just training on PROMs and IT.

The Purpose of PROMs



- PROMs, and what is done with those PROMs, should be centred around what matters most to the patient. The patient's personal goals should be understood, which may help steer decisions around what PROMs to collect, and what to do with the information, both during and in between appointments.
- Managing patient expectations is important, and can look like:
 - Clearly explaining to patients what PROMs are and why they are collected
 - Explaining to patients that being honest in their responses will not necessarily result in treatments they want to be on being taken away from them, but can help keep them safe and open up wider areas of support
 - Ensuring that the PROMs that are collected link with clinical solutions (such as medicines or care pathways) that patients could receive in real life
 - Ensuring that only data that will be used to help inform care, treatment decisions or monitor patient quality of life are collected
- There is a need for both standardised/national PROMs as well as local variation/flexibility. Additional/open-ended questions can be used to obtain more information from patients when needed.
- Accessibility considerations of importance are: languages, disability, health and IT literacy, low confidence and lack of IT access. Some of these could be supported with patient education.
- Moving from PROMs "data" to "intelligence" is key- information to be visualised well, available over time as well as at individual patient and population levels, and need to be quickly digestible for all.
- PROMs can be treated "just like other data" and viewed alongside clinical data to get the broader view of the patient experience.

The Pathways and Processes



- Considering what **clinical pathways** are suitable for early adoption of PROMS – there was a discussion about pathway complexity and whether it would be more beneficial to start in a condition such as head and neck cancer (more complex with a lot of clinical interactions early on) versus keeping it simple to begin with. There was no clear consensus.
- There was agreement that PROMs should be measures that are used to either trigger an action or an alert, or are used to make comparisons between patients, clinicians, or services.
- The Cancer Treatment Helpline process is an exemplar of how PROMs could work in practice. A checklist is completed when patients call and the outcomes are visible to the patient’s GP and secondary care. However, the data are not structured/available in a reusable format– as yet.
- When discussing **digital pathways and processes**, participants felt “digital integration” generally meant that the PROMs digital platform could be accessed within existing core work digital systems (e.g. the patient’s electronic health record application).
- When providing individual patient care, the clinician having to log into another system to view PROMs may be a barrier to uptake.
- Although digital integration is almost always possible, to get a third-party application fully integrated with an existing NHS electronic health record will require dedicated resource from NHS software engineers and informaticians – the resource needed for this is the major barrier.
- Consequently, another barrier is that there are currently no known examples where full digital integration has been realised, upon which best practice could be based on and learned from.

The Unintended Problems



- **Preventing patient burden is priority.** Patients may already be fatigued, and could be overwhelmed by answering lots of questions. PROMs should improve not harm quality of life. Some solutions could include:
 - Focusing on core questions and consider which PROMs would be the most helpful (and why)
 - Offer simplified versions of PROMs tools to those patients who would benefit as an alternative.
- **The risks of PROMs** being used in making automated care or follow-up decisions were acknowledged. This could cause increased service demand as well as “missing” patients who need clinical evaluation:
 - PROMs should be used as near-real time as possible, and using traffic light systems could help clinicians assess which patients need clinical evaluations most
 - Tracking the rate of alerts that come from PROMs, the effectiveness of automated interventions, and adjusting the service as a result, would be needed.
- **Hybrid systems** (both electronic and paper PROMs) require staff to manually enter PROMs data, which would cause resource issues.
- Collecting PROMs may **raise additional yet legitimate issues** than what can be addressed effectively and timeously by clinical teams.
- PROMs **may pick up on mental health concerns**, which are often present after treatment. There is a need to think about: who needs to see those data; who can respond; whether data is able to map out the support structures and show clear pathways for patient care; and how that data may help inform patients’ future treatment decisions.
- How we account for **missing data in PROMs** (where patients have chosen not to complete PROMs tools in full) needs to be considered.

Key Recommendations

The Core Principles appear to be focussing on the right kinds of considerations, and implementing them should address the challenges experienced to help achieve Scotland's PROMs ambitions. We encourage all stakeholders to consider the PROMs Core Principles in any PROMs work they are undertaking.

For clinicians and clinical teams

- If PROMs are available to you, consider how you could support their implementation through adjusting your own way of working, starting small and building up.
- It's important for patients / carers to have easy access to PROMS early on in their care pathway. Making patients aware and encouraging them to ask questions about PROMs is key to its success.
- Provide the patient with feedback on their PROMS, integrating findings into your assessment and management plan. This can build patient confidence.
- If PROMs are not available, discuss with colleagues / managers what value they may bring to their system/patient care.

For Decision Makers

- Health organisations (e.g. Health Boards) have a role in promoting PROMs to their staff, patients and the public.
- Public information campaigns would help improve public knowledge of PROMs. These could come through utilising social media platforms, relevant websites etc. to increase public / patient awareness.
- Consider your current service pressures and processes, and how PROMs could support innovation or improvement in these areas.
- If collecting PROMs, plan for and monitor potential risks – data and alert overwhelm, burden on patients etc.

For Innovators

- One of the main barriers to success in PROMs is digital integration. Work closely with NHS organisations to understand their data governance and structures in place.

For Patients & The Public

- If you are a patient, or caring for someone who is, ask your clinical team to explain about PROMs and ask whether they can be used to support you and your care.
- Continue to have conversations with your clinical team about what matters most to you. Ask yourself what support needs you might have, including psychological / emotional. Perhaps write them down and discuss them with your clinical team.
- Attend future Scottish Cancer PROMs Forum events and share your views on how PROMs should be used and collected in Scotland heard. Ways to keep in touch are included on the last page of this report.

What Next?

Next Steps

- The Scottish Cancer PROMs Advisory Group will take the information gathered and use it to build the Scottish Cancer PROMs toolkit, which will include (not exclusively):
 - Detailed PROMs Core Principles
 - Links to useful resources and networks
 - Possible training resources
 - Key contacts

Other Information

During the breakouts, participants made reference to some interesting reports and publications. These are provided below.

- Macmillan Cancer Support's Improving the Cancer Journey – includes [a Holistic Needs Assessment \(HNA\)](#)
- King's Fund Report– [Patient Preferences Matter](#)
- Hacking et al (2012) [Testing the feasibility, acceptability and effectiveness of a 'decision navigation' intervention for early stage prostate cancer patients in Scotland--a randomised controlled trial](#)

Presenter Biographies

Anne Leitch – *Value Based Healthcare Programme Lead, Scottish Government*

"I started my nursing career in 1987 at Law Hospital, Carluke. I have worked within NHS Lanarkshire for over 30 years specialising in critical care, infection, prevention and control and senior nursing roles. Laterally I was Chief Nurse at University Hospital Wishaw where I had responsibility for professional nursing, encouraging innovation, creativity and strategic thinking about service provision. As part of my roles, I have been actively involved in various initiatives focusing on leadership and quality improvement, which include local, operational, strategic and national work. In February 2022, I was appointed as Value Based Health and Care Programme Lead within the Realistic Medicine team based in Scottish Government. My role involves providing strategic advice that informs and supports development and implementation of a value based health and care vision for Scotland. I provide support and leadership around the implementation of value based health and care and I work closely with our health and care stakeholders, including Realistic Medicine Networks within NHS Boards, and professional representative bodies. My personal interests include exercise; I do love a spin class, family time and socialising with friends."

Dr Kathrin Cresswell – *Senior Lecturer, University of Edinburgh*

Kathrin Cresswell is a social scientist with extensive experience in conducting formative evaluations of digitally enabled change and improvement programmes in healthcare. She has consulted for the World Health Organization, Harvard Medical School, NHS England and Improvement, and is a member of the International Academy of Quality and Safety in Health Care, the Royal Society of Edinburgh Young Academy of Scotland. She is also the co-chair of the International Medical Informatics Association (IMIA) and European Federation of Medical Informatics Evaluation Working Groups on evaluation. She is currently a Senior Lecturer at the Usher Institute at The University of Edinburgh, and Course Lead on a Scottish national digital health leadership programme. She has researched the use of a variety of health information technologies in context over almost years. These have included both patient- and professional-facing technologies comprising electronic health records, robotics, health and fitness apps, artificial intelligence and decision support systems. She is an expert in conducting evaluations of digital applications, having applied formative methods in a variety of health and care settings (hospitals, primary care, and home). Bringing together stakeholders with varying perspectives is key to her ongoing work, where she examines how political, commercial, organisational, patient and healthcare workers' interests need to be aligned to transform health and care through safe and scalable technologies.

Prof Robin Williams – *Director – ISSTI, University of Edinburgh*

Robin Williams was recruited to the University of Edinburgh to lead its successful bid under the ESRC Programme on Information and Communication Technologies (1987–95). This formed the basis for an interdisciplinary programme of research into 'the social shaping of technology' with over 60 externally-funded research awards. Interdisciplinary research collaborations collaboration with practitioners and specialists from science and engineering, including work on the dependability of computer based systems occasioned an increasing involvement in health information technology research. In collaboration with Kathrin Creswell (Usher Institute) he led the Independent Evaluation of NHS England's flagship Global Digital Exemplar programme.

He founded and directs the Institute for the Study of Science, Technology and Innovation, which brings together researchers across the University of Edinburgh in these linked domains. He is chair of the UK Association for Studies of Innovation, Science and Technology.

Scottish Cancer PROMs Advisory Group Executive Team

Dr Peter Hall – *Reader and Consultant Medical Oncologist, Edinburgh Cancer Research Centre, University of Edinburgh; Edinburgh Health Economics Group Lead, Edinburgh Clinical Trials Unit & Co-Chair of the Scottish Cancer PROMs Advisory Group*

Peter is an academic Medical Oncologist with a research interest in Health Economics, Data Science and Health Technology Assessment in Cancer. The focus of his research is on the development of improved methods for efficient research design, cost-effectiveness analysis and the measurement of clinical and socioeconomic outcomes using data obtained from clinical trials and routinely collected within health systems. He leads the Edinburgh Cancer Informatics Programme which provides healthcare data analytical capabilities for both NHS Cancer Services in South East Scotland and the CRUK Scotland Centre's research programmes. He treats patients with breast cancer within the NHS at the Edinburgh Cancer Centre..

Emma Dunlop – *Research Associate, Strathclyde Institute of Pharmacy & Biomedical Sciences, University of Strathclyde & Co-Chair of the Scottish Cancer PROMs Advisory Group*

Emma is a researcher in the Pharmacoepidemiology & Health Care Research Group at the University of Strathclyde, since around 2011. She works full time on the Scottish Government funded Cancer Medicines Outcomes Programme, which is a national collaboration between the University of Strathclyde, NHS Boards and Public Health Scotland (CMOP-PHS). The main aim of CMOP-PHS is to understand the real world impact of cancer medicines on patients in Scotland. Emma has been working on patient reported outcome measures since 2016. Emma is also passionate and active in patient and public involvement.

Debbie Provan – *Clinical Advisor, Cancer & Rehabilitation Unit, Scottish Government*

Debbie is a Clinical Advisor to the Scottish Government's Cancer and Rehabilitation Unit. She is responsible for a number of actions within the current Cancer Action Plan and 10-year Cancer Strategy, including those which focus on prehabilitation, single point of contact and patient reported outcome measures (PROMs). With a background in Dietetics, she has worked in cancer services for a number of years, spending a significant time supporting the delivery of Scotland's Transforming Cancer Care Programme through Regional Clinical Lead and National AHP Lead roles.

Kevin Gallagher – *Specialist Trainee in Urological Surgery, NHS Lothian, Fellow for Data Driven Innovation, Public Health Scotland, Clinical Lecturer University of Edinburgh*

Kevin is a Specialist Trainee in Urological Surgery, Academic Clinical Lecturer in Urology at the Cancer Informatics Group, University of Edinburgh and Clinical Fellow for Data Driven Innovation with the Centre for Sustainable Delivery / Public Health Scotland. Kevin has an interest in using real world healthcare data more effectively for quality improvement and incorporating patient reported outcome measures in this. Kevin leads a national programme collecting patient reported outcome measures after prostate cancer treatment. He also leads a global cluster randomised controlled trial testing a digital performance feedback intervention to improve quality in bladder cancer surgery.



This report of the SC PROMs Forum event was written by the SC PROMs Forum & Advisory Group Executive Team, with thanks to the CMOP-PHS Patient & Public Representatives for their contribution.

Thank you to the breakout facilitators, whose notes formed a key part of this report.

Emma Dunlop– Co-Chair of the SC PROMs AG, Research Associate, CMOP-PHS, University of Strathclyde

Peter Hall– Co-Chair of the SC PROMs AG, Academic Medical Oncologist, University of Edinburgh

Debbie Provan– Clinical Advisor – Cancer and Rehabilitation Unit, Scottish Government

Kevin Gallagher– Specialist Trainee in Urological Surgery, NHS Lothian, Fellow for Data Driven Innovation, Public Health Scotland, Clinical Lecturer, University of Edinburgh

To find out more about the Forum or Advisory Group, please contact
PHS.CMOP@phs.scot

Or follow CMOP-PHS on X© (formerly Twitter©) @cmoprogramme

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