Scottish Cancer Patient Reported Outcome Measures Forum

KEY LEARNING & RECOMMENDATIONS FROM MEETING 2 – 25TH NOVEMBER 2022

The 2nd SC PROMs Forum event 25th Nov 2022

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; and,**
- **to better understand and manage the impact that cancer medicines have on quality of life.**

The Forum supports the Advisory Group in developing a set of core principles for the collection and use of PROMs in clinical practice in Scotland.

At the time of the event, the Core Principles (key values on how Scotland can include PROMs in routine care) had been informed by the current evidence base and members of the Advisory Group. The aim of the Forum event was to support the development of the Core Principles. The event showcased some examples of PROMs used in clinical practice. Attendees could pose questions to speakers and panel members, before taking part in workshops, each one centred around a PROMs Core Principle.

The presentations from Dr Sally Lewis and Dr Said Shadi (slides attached) gave great insight into PROMs developments in Wales. Each of the workshops were incredibly valuable in understanding the opportunities and challenges our diverse range of attendees saw in the Core Principles. The panel discussion brought ideas together, helping to bring a fresh perspective to the Core Principles.

On the next pages you will find:

- a summary of our key messages and recommendations from the event
- the agenda, plus biographies of each speaker, workshop chair, facilitator and panel member
- key resources suggested by the attendees
- details of how to get more information on the Forum and Advisory Group.

Many thanks to the presenters, chairs and facilitators who contributed to the event, and to all the attendees for your enthusiasm. Thanks to the Executive Team for organising the event, and the SC PROMs Advisory Group for their steer and support.

What Did We Learn?

WORKSHOP A: What PROMs are most important to measure?
CHAIR: Anne Leitch, *Value-based health and care Lead, CMO Division, Scottish Government*
FACILITATOR: Debbie Provan, *Clinical Advisor, Cancer Policy Team, Scottish Government / SC PROMs Advisory Group Executive Team*

- **There is not enough clear information on PROMs,** and the landscape is cluttered. This makes implementing PROMs in routine care challenging.
- **International Consortium for Health Outcome Measurement (ICHOM) was named as a reliable resource** for tested and validated PROMs tools. However, moving from research to reality, some questions included are not appropriate. More published examples of PROMs used in routine care would be of benefit.
- **In PROMs research, theoretical frameworks are often used,** and we can use this approach to move forward in exploring what matters most to people.
- **PROMs could be used to predict who is likely to need additional support**, especially regarding how confident people are in managing their condition.
- **Depression, mental health, confidence to manage own condition and social support** are important areas to cover with patients.
- **Digital PROMs could help to capture issues** more proactively alongside the 24 hour cancer helpline but require staff to monitor and respond to issues.
- **PROMs should be person-centred, collected as early as possible in the patient's journey and repeated throughout treatment,** while keeping in mind that this could be burdensome for some patients although valuable in the long term.
- **There is a need for more joined up systems** so that patients with multiple conditions are not being asked the same questions over and over.
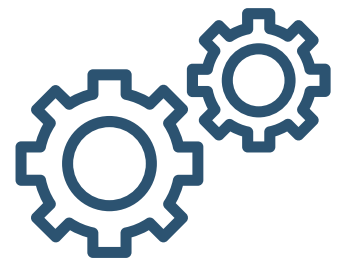
WORKSHOP B: Making PROMs part of routine care
CHAIR: Lisa MacLeod, *Lead Pharmacist, Scottish Cancer Network*
FACILITATOR: Dr Peter Hall, *Co-Chair of the SC PROMs AG, Academic Medical Oncologist, University of Edinburgh*

- **Clinical practice is different from research** and we need to adapt the learning from research.
- **Sustainable investment is needed long-term** in staff, time, training, change management, culture change etc.
- **The objectives of PROMs need to be clear and relevant** for staff and patients investing their time: are they for understanding the patient experience, for managing care, or for audit?
- **We don't need to start with PROMs.** Launching digital solutions where patients can interact with the health service more easily (e.g. electronic appointment systems) may be a good route in.
- **Population-level approach may be an easy place to start** but to move to PROMs in routine care, the tools and platforms needed may need to change.
- **Barriers to accessing PROMs need to be addressed early on**.
- **Simplicity is a success factor**. For example, PROMs delivered through a simple link in an email to patients.
- **PROMs need to be part of shared decision making**. PROMs should be blended in with clinical conversations so patients and their clinicians can make the right decision.
- **It's important that PROMs are complete by patients and/or carers themselves** (with support if needed).
- **Interoperability is key to success.** National data and interoperability standards (ideally internationally) need to be adhered to.
- **A national approach to PROMs doesn't need to mean one national app** – local variation should be accommodated.
- **Progress over perfection** should be the way forward for PROMs.

WORKSHOP C: Making digital PROMs accessible and inclusive
CHAIR: Margaret Greer, *Partnership Assurance Lead, Macmillan Cancer Support*
FACILITATOR: Kelly Baillie, *Co-Chair of the SC PROMs AG, Senior Clinical Effectiveness Pharmacist, Cancer Medicines Outcomes Programme, NHS Greater Glasgow & Clyde*

- **A collaborative approach is needed** alongside health, social care and third sector. People in the group referred to the innovation hubs (see Resources on page 6).
- **We need some local standardisation and local collaboration as well as national approach** through the Scottish Cancer PROMs Advisory Group.
- **A core group of PROMs for different cancer areas with common themes could help organise what is a cluttered landscape.**
- **Patient & public involvement in the design and testing of PROMs is essential** to make the language accessible. Any digital solutions also need to be tested and adapted if needed.
- **Engaging the community (not just clinicians) will help address IT challenges** – for example, job centres supporting patients with IT and building on the work through Scottish Government's Connecting Scotland
- **The workforce's IT skillset is a challenge.** Healthcare professionals who would be using PROMs need training and support, not just the patients.
- **There are workforce pressures to consider.** Although PROMs could alleviate these, they could also pose a burden. Volunteers could help support (e.g. showing patients in-clinic how to use PROMs).
- **Keeping the patient as the focus is essential.** PROMs can help to shape treatment decisions, but a holistic approach to PROMs overall is important.
- **We need to keep up with the diversity of Scotland.** As communities become more diverse, PROMs need to be available in more languages, for example.

What Next?

Some of the Forum outputs reinforce messages already captured in the current draft of the Core Principles. The SC PROMs AG will redraft the Core Principles based on the Forum findings with a focus on incorporating the following:

The Core Principles will advocate for standardised PROMs. There should also be flexibility for additional PROMs depending on where the patient is on their cancer pathway.

PROMs tools measuring treatment toxicity as well as psychosocial impacts on quality of life are important. Toxicity recording may be a good a starting point for new PROMs adopters.

The Core Principles will advocate for PROMs to be completed directly by the patient and/or carer (with support where needed).

The Core Principles are currently aimed at clinical teams and digital providers. Collaboration with colleagues in the wider health & social care arena should be considered in order to support PROMs uptake and share learning & insight.

Resources

The following resources were mentioned by attendees during the event. Please click on the links below for more information.

WEBSITES & INFORMATION

Innovation Hubs: Work together to improve health and social care and support innovation across the **West of Scotland**, **South East Scotland** and **NHS Grampian**.

ICHOM: International Consortium for Health Outcome Measurement. Part of their mission has been to define global Sets of Patient-Centered PROMs that matter most to patients.

CEDAR (WALES): Cedar has a team of researchers dedicated to the National Value in Health (ViH) Programme, which strives towards achieving a Value-Based Health Care approach across NHS Wales.

Patient connect: Mobile app for Android phones which allows patients with their electronic health record linked with PatientClick to access their information over the web and contact their offices easily.

RESEARCH PAPERS

What matters to patients and clinicians when discussing the impact of cancer medicines on health-related quality of life? Consensus-based mixed methods approach in prostate cancer (Dunlop et al 2022): Research by the Cancer Medicines Outcomes Programme (CMOP) on what matters most to prostate cancer patients and clinicians when discussing the impact of treatment on quality of life. Published in Supportive Care in Cancer.

The implementation and impact of Holistic Needs Assessments for people affected by cancer: A systematic review and thematic synthesis of the literature (Johnston et al 2019): The first review of the research on whether the way in which health needs assessment is implemented impacts on patient outcomes. Published in the European Journal of Cancer Care

SC PROMs Forum Meeting 2 Agenda

INTRODUCTION		
Welcome from Scottish Cancer Patient Reported Outcome Measures Advisory Group (SC-PROMs AG) and introduction to the SC-PROMs Forum	10:00am	**Kelly Baillie** (*Senior Clinical Effectiveness Pharmacist, Cancer Medicines Outcomes Programme (CMOP) NHS Greater Glasgow & Clyde, and Co-Chair of the Scottish Cancer PROMs Advisory Group*)
Plenary Session: *Standardising PROMs collection and utilisation across Wales* Questions	10:05am	**Dr Sally Lewis** (*Director of the Welsh Value in Health Centre, National Clinical Lead for Value-Based and Prudent Healthcare, NHS Wales*)
Presentation: *Wales Value in Healthcare PROMs Standard Operating Model (PSOM)* Questions	10:25am	**Dr Said Shadi** (*Chief Digital Officer and Head of PMO, Welsh Value in Health Centre*)
Pre-workshop talk: *Scottish Cancer PROMs Core Principles*	10:40am	**Emma Dunlop** (*Exec Team for the Scottish Cancer PROMs Advisory Group / University of Strathclyde*)
WORKSHOPS (see description below)	10:45am	
WORKSHOP A: What PROMs are most important to measure?		
Discussion around what would be the most useful outcomes that should be collected across *all* cancer patients in Scotland (e.g. certain symptoms, side effects, impact of treatment on mental health & well-being etc.). Including discussion on what would add most value to the decisions patients/clinicians make about treatment option(s), and any other relevant considerations.		
WORKSHOP B: Making PROMs Part of Routine Care		
Discussion on how the collection and use of digital PROMs should be integrated into the current patient care, and how they should work alongside existing IT systems in the NHS, as well as any challenges and potential solutions to digital PROMs integration.		
WORKSHOP C: Making digital PROMs Accessible and Inclusive		
Discussion on how digital PROMs can be made inclusive and accessible to all patients. Including the support that patients may need when providing PROMs information (technologically and personally), and how we ensure those patients who cannot or choose not to provide PROMs data are not forgotten.		
BREAK		
PANEL DISCUSSION		**Chair: Dr Peter Hall**
Sharing what was discussed in the workshops	11:40am	**You can ask questions and make comments using the Q&A function.**
Closing Remarks	12:25pm	**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*
CLOSE		

Presenter, Workshop Chair, Facilitator & Panellist Biographies

Dr Sally Lewis

Sally is a GP and has front-line experience of primary care at its most challenging. She entered a career in medical management in 2011 and was appointed to Assistant Medical Director for value-based care in the Aneurin Bevan University Health Board in 2014. Since 2018, Sally has been leading the national value-based healthcare programme in Wales which is now part of the World Economic Forum's Global Coalition for Value Based Health Care. She is an Honorary Professor at Swansea School of Medicine.

Said Shadi

Said Shadi leads the digital agenda for the Welsh Value in Health Centre and directs the Portfolio Project Management Office (PMO). The PMO manages the delivery of national value-based healthcare transformational change programmes, spanning clinical areas, research/development, industry partnerships, digital and data. In a career spanning more than 30 years, Said has had a varied and extensive exposure to digital, technology and data across the private and public sectors. He has extensive experience of strategically leading major business transformation programmes within Banking and Finance organisations before joining National Health Services (NHS) Wales. Prior to the Welsh Value in Health Centre, Said established a specialist function responsible for the national digital enterprise application for the Finance, Procurement and Supply Chain communities across NHS Wales. During this period, he led the delivery of one of the largest QlikView BI reporting deployments in Europe and an intelligent document scanning service processing circa 1 million invoices per annum. Said is passionate about digital technologies, analytics and seeking valuable insights from data. Said is a Computing graduate, earned a Doctorate from Cardiff University, researching intelligent process automation and the future of work and earned an Executive MBA from Swansea University. Said qualifications extents across many relevant subjects, including: Artificial Intelligence, Machine Learning, ITIL Expert, Practitioner in Project, Programme and Risk Management and Lean/Six Sigma Black Belt.

Anne Leitch

"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 healthcare 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."

Lisa MacLeod

Lisa MacLeod is a part-time lead pharmacist with Scottish Cancer Network and a PhD candidate with the University of Stirling. Her research interests are new models of care for cancer patients and her current work includes a community pharmacy pathway for the administration of subcutaneous trastuzumab and ongoing development of an educational programme for community pharmacists, Let's Communicate Cancer.

Margaret Greer

Margaret Greer is a member of the Digital Health and Care Scotland's Digital Nursing, Midwifery and Allied Health Professionals (dNMAHP) Leadership Group. She is a Partnership Assurance Lead, implementing the national Transforming Cancer Care programme with third sector charity Macmillan Cancer Support. Her role focuses on improving outcomes for people affected by cancer through a personalised, holistic care approach. Digital lead for Macmillan in Scotland, Margaret works closely with Board Leads across Health and Social Care Partnerships.

Scottish Cancer PROMs Advisory Group – Co-Chair & Exec information

Dr Peter Hall (Co-Chair)

Peter Hall is an academic Medical Oncologist with a research interest in Health Economics, Data Science and Health Technology Assessment in Cancer. He treats patients with breast cancer within the NHS at the Edinburgh Cancer Centre. 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.

Kelly Baillie (Co-Chair)

Kelly is a senior Pharmacist working in NHS Greater Glasgow & Clyde and has specialised in cancer care since 2005. She is currently a Senior Clinical Effectiveness pharmacist for the Cancer Medicines Outcome Programme (CMOP) which is a National Collaboration between NHS boards in Scotland and the University of Strathclyde. CMOP aims to use routinely captured healthcare data to better understand the real life impact of cancer medicines used to treat cancer patients in Scotland.

Emma Dunlop

Emma Dunlop is part of the Scottish Government-funded Cancer Medicines Outcomes Programme (CMOP). Emma's role focuses on how best to make PROMs part of routine practice in cancer care in Scotland. Emma is a Research Associate at the Strathclyde Institute of Pharmacy & Biomedical Sciences, University of Strathclyde, where she has worked in Health Service Research for over a decade.

Debbie Provan

Debbie is a Clinical Advisor to the Scottish Government's Cancer Policy Team. She leads on a number of National Cancer Plan actions including those which focus on pre-habilitation, single point of contact, the cancer patient experience survey and patient reported outcome measures. 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 Care After Treatment Programme in Regional Clinical Lead and National AHP Lead roles.

This report of the SC PROMs Forum event was written by the SC PROMs Advisory Group & Forum Executive Team, with thanks to the Cancer Medicines Outcomes Programme Patient Representatives and Patient Network for their contribution.

Kelly Baillie– Co-Chair of the SC PROMs AG, Senior Clinical Effectiveness Pharmacist, Cancer Medicines Outcomes Programme, NHS Greater Glasgow & Clyde

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

Emma Dunlop– Research Associate, Cancer Medicines Outcomes Programme, University of Strathclyde

Debbie Provan– Clinical Advisor – Cancer Policy at The Scottish Government

Please read our Summary Report from the SC PROMs Forum Meeting 1 (March 2022) HERE

If you are currently working with PROMs and would like to share your experiences, or to find out more about the Forum or Advisory Group, please contact ggc.cmop@ggc.scot.nhs.uk

Jan 2023