



Scottish Cancer Patient Reported Outcome Measures Forum

KEY LEARNING & RECOMMENDATIONS FROM
MEETING 1 - 25TH MARCH 2022

The 1st SC PROMs Forum event 25th March 2022

The online event featured a comprehensive agenda with 9 speakers and panellists including patients and those working with PROMs in research and clinical practice. 176 people registered and 133 attended. Since PROMs can help us understand how cancer treatment impacts quality of life, the aim of the event was to build an understanding of how PROMs are currently being used, and what the challenges and opportunities are for implementation in Scotland. The presentations were diverse, yet all provided valuable contribution to working towards a more cohesive approach to PROMs in Scotland.

On the next pages you will find a summary of our key messages and our recommendations from the event. At the end you will also find a copy of the agenda, biographies of each speaker and panel member, 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 medicines 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 panelists who contributed to the event, all of the attendees who tuned in 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.

What Did We Learn?

- Patients have valuable input – patient involvement in the process of PROMs design, implementation & review is essential
- There are known benefits and barriers to PROMs, and clearly defining / communicating these is important
- Need to ensure ALL stakeholders are clear on the purpose and potential benefits of PROMs data to maximize engagement and success (e.g. patients need assurance that their data will be reviewed by their clinicians)
- To maximise patient compliance / adherence to using digital PROMs, the question format and number of questions needs to be considered
- Standardised PROMs tools / questions are required, but there is potential need for variation with different pathways, treatments / conditions
- Access & health equality considerations – essential to not leave any patients behind when adopting digital PROMs into care
- Digital integration with current NHS systems is key – PROMs software needs to integrate fully and not be a standalone platform
- Strong clinical leadership and building PROMs into existing processes are critical factors for success.

What Next?

Key Recommendations

- The benefits to PROMs should be clearly communicated to help those who are developing the use of PROMs in order to draw on these benefits, and overcome potential barriers
- Consider creating a minimum specification for PROMs software / applications for digital technology suppliers
- Continue to track existing and emerging cases where PROMs are used in clinical practice, and work with clinical teams to explore the suitability of different PROMs tools in different areas
- Create an implementation guide to overcome barriers which limit the potential of PROMs from both patient and clinical / systems perspectives
- Although the Advisory Group has Charity representation, the Advisory Group should look to include patient representation as part of their membership.

Next Steps

- This report will be shared with the Scottish Cancer PROMs Advisory Group
- Learning from this first Forum meeting will be used to help shape and plan for future meetings.

Scottish Cancer PROMs Forum Meeting 1 Programme
Friday 25th March 10am – 12:30pm via MS Teams Live

INTRODUCTION		Chair: Peter Hall
Welcome from SC-PROMs AG and introduction to SC-PROMs Forum	10:00am – 10:05am (5 mins)	Kelly Baillie (<i>Senior Clinical Effectiveness Pharmacist, Cancer Medicines Outcomes Programme (CMOP) NHS Greater Glasgow & Clyde, and Co-Chair of the Scottish Cancer PROMs Advisory Group</i>)
Plenary Session: <i>Standardising PROMs collection and utilisation across Wales*</i>	10:05am – 10:20am (15 mins)	Dr Sally Lewis (<i>Director of the Welsh Value in Health Centre, National Clinical Lead for Value-Based and Prudent Healthcare, NHS Wales</i>)
SECTION A: Patient Involvement in ePROMs studies		Chair: Kelly Baillie
<i>Electronic Patient-Reported Outcome Measures (ePROMs) in Clinical Practice: The Christie Patient Perspective</i>	10:20am – 10:35am (15 mins)	Dr Cathryn Crockett (<i>Locum Clinical Oncology Consultant, Northern Ireland Cancer Centre, Belfast</i>)
Questions for presenter	10:35am – 10:40am (5 mins)	
SECTION B: Use of PROMs in the real world- examples of research and clinical practice		Chair: Kelly Baillie
<i>Real time remote symptom monitoring using PROMS during chemotherapy for cancer: European multicentre randomised controlled trial (eSMART)</i>	10:40am – 10:55am (15 mins)	Prof Roma Maguire (<i>Professor of Digital Health and Care, University of Strathclyde</i>)
Questions for presenter	10:55am – 11am (5 mins)	
<i>Online symptom monitoring: eRAPID trials and implementation challenges</i>	11am – 11:15am (15 mins)	Prof Galina Velikova (<i>Professor Psychosocial and Medical Oncology, University of Leeds</i>)
Questions for presenter	11:15am – 11:20am (5 mins)	
<i>My Clinical Outcomes / Using PROMs in Pre-Chemotherapy Toxicity Assessment</i>	11:20am – 11:35am (15 mins)	Tim Williams / Dr Peter Maclean (<i>Co-founder & CEO of My Clinical Outcomes (MCO)/ Clinical Director for Cancer at NHS Ayrshire & Arran</i>)
Questions for presenter(s)	11:35am – 11:40am (5 mins)	
Comfort Break	11:40am – 11:50am (10 mins)	
PANEL DISCUSSION		Chair: Dr Peter Hall
Topic: Developing a key set of PROMs principles for clinical practice in Scotland	11:50am – 12:25pm (35 mins)	Panel includes the above speakers as well as Prof Aileen Keel CBE (<i>Director, Innovative Healthcare Delivery Programme, Usher Institute, University of Edinburgh</i>), Steph Wright (<i>Head of Scottish AI Alliance Support Circle, The Data Lab</i>), Chaloner Chute (<i>Chief Technology Officer, Digital Health & Care Innovation Centre</i>), Ally Boyle MBE (<i>CMOP Patient Representative, Non-Exec Director of NHS Lanarkshire & Trustee at Blood Cancer UK</i>)
Closing Remarks	12:25pm – 12:30pm (5 mins)	Dr Peter Hall (<i>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</i>)
CLOSE		

*Dr Sally Lewis was unable to present on the day

Presenter & 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.

Dr Cathryn Crockett

Cathryn is currently working as a locum Clinical Oncology consultant in the Northern Ireland Cancer Centre in Belfast, specialising in lung, head and neck and skin cancers. Prior to this, Cathryn completed a two-year clinical research fellowship in lung cancer and advanced radiotherapy techniques under the supervision of Prof. Corinne Faivre-Finn at the Christie NHS Foundation Trust. During her fellowship, which concluded in February 2022, Cathryn was involved with the ongoing implementation and development of the Christie ePROMs service.

Prof Roma Maguire

Roma Maguire is a Professor of Digital Health and Care at the University of Strathclyde and Director of the Health and Care Futures initiative. She is also co-lead of the Health Technology Cluster and holds an Honorary Nurse Consultant post in Digital Health at NHS Lanarkshire. Her research interests include Digital Health, Remote Patient Monitoring, Supportive Care, Predictive Modelling and Values Based Medicine. She has significant experience in the co-design, development, evaluation and implementation of person-centred remote patient monitoring systems using patient reported outcome measures (PROMs) to optimise symptom management, promote adherence to medicines, support wellbeing and improve quality of life. Her research spans several clinical specialities including cancer, dementia, cardiac and respiratory disease and palliative/end of life care. She has led several multi-site supportive care and digital health studies in the UK and across Europe.

Prof Galina Velikova

Professor Galina Velikova is an academic Medical Oncologist at the University of Leeds and Leeds Teaching Hospitals, UK, with over 20 years' track record of successful patient-centred research using electronic Patient-Reported Outcome Measures in daily practice and clinical trials. She led a National Institute for Health Research (NIHR) 5-year Programme Grant for applied research on patient self-reported symptoms and toxicity, using an online reporting system (QTool), uniquely integrated in electronic records, along re-designed care pathways for remote monitoring during cancer treatment to improve patient safety. Further research projects evaluate the use of the electronic system for remote monitoring and follow-up of cancer patients after treatment.

Professor Velikova has experience in leading collaborative research, both nationally and internationally, such as Quality of Life sub-studies of international breast cancer trials (TACT2, SUPREMO). She is on the Steering Committee for the NHS England national quality-of-life metric project for cancer survivors. Professor Velikova is the past Chair of the British Psychosocial Oncology Society; past Chair of the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group; and past President of the International Society for Quality of Life Research (ISOQOL). Professor Velikova is currently the Chair of the National Cancer Research Institute (NCRI) Living with and Beyond Cancer Group and was an elected board member of the EORTC from 2018 – 2021. Professor Velikova is a practising oncologist (Consultant in Medical Oncology) with clinical work focused on systemic treatment of breast cancer patients with early and advanced disease.

Dr Peter Maclean

Peter Maclean has been a Consultant Haematologist in Ayrshire since 2008 and Clinical Director for Cancer Services at NHS Ayrshire & Arran since 2009. At the start of his consultant career, Peter's main area of interest was coagulation, now the majority of his clinical time is spent in Haemato-oncology and in the prescribing of chemotherapy in particular. Improvement in the processes around safe prescribing and delivery of chemotherapy has therefore over the years become one of Peter's major goals.

Tim Williams

Tim is the Co-founder & Chief Executive Officer (CEO) of My Clinical Outcomes (MCO). Tim started MCO in 2011 having previously worked as a junior doctor in the NHS and Australia and as a management consultant in the NHS for several years.

Prof Aileen Keel CBE

Aileen Keel is seconded from Scottish Government to the Usher Institute at the University of Edinburgh to lead the Innovative Healthcare Delivery Programme (IHDP). Aileen joined the Scottish Office (as was) as a Senior Medical Officer in the Department of Health in 1992. She was Deputy Chief Medical Officer in the Scottish Government Health and Social Care Directorates from 1999 to 2014. Between April 2014 and May 2015 she was acting Chief Medical Officer. She is Chair of the Scottish Cancer Task Force (paused at present due to the pandemic), Chair of the National Cancer Recovery Group, Co-chair of the Scottish National Audit Programme Board (Health), and has an Honorary Chair at the University of Edinburgh. She retired from clinical practice in haematology in 2017.

Steph Wright

Steph is the Director of Health and Wellbeing Engagement, The Data Lab. Steph is a data science enthusiast with specific experience of the healthcare domain. She has been extensively involved in developing and building collaborations across organisations as well as experience in project and programme management. Steph has a diverse background ranging from astrophysics to genomics in academia and film & TV to dance in the arts and the third sector. She led on the Cancer Innovation Challenge, a £1M project to improve cancer care through innovative use of data including PROMs and PREMs.

Chaloner Chute

Chal is the Chief Technology Officer, Digital Health & Care Innovation Centre (DHI). Chal leads on DHI's technical strategy and is responsible for the way we support and deliver technical innovation, by applying systems thinking and methodologies in support of the DHI innovation model. He is devoted to the idea that citizens can be empowered to take an active role in their own wellbeing.

Ally Boyle MBE

Ally was a firefighter for over 20 years but had to retire in 2014 due to developing the blood cancer myelodysplasia. He had a significant expertise for prevention, partnership working and involvement within the fire service and has utilised this and his diagnosis to try to make a difference for others. He formed a lifesaving partnership between the fire and rescue service and the blood cancer charity Anthony Nolan and also has become a champion for patient involvement. He is the co-chair of Cancer Research UK's Joint Patient and Public Involvement Panel for the Prevention and Population and the Early Detection and Diagnosis Research Committees and also a member of CRUK's Cancer Insights Panel. His mantra is "Nothing about us without us" as he truly believes that the best solutions are those that come through working with the people affected. He is a Non-Executive Director with NHS Lanarkshire, Chair of their Population Health Governance Committee and is a Trustee and proud supporter of Blood Cancer UK. He is also one of CMOP's Patient Representatives.

Scottish Cancer PROMs Advisory Group – Co-Chair information

Dr Peter Hall

Dr 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

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.

This report of the SC PROMs Forum event was written by the SC PROMs Forum & Advisory Group 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

Ruairidh Anderson– Policy Manager, Scottish Government

To find out more about the Forum or Advisory Group, please contact
ggc.cmop@ggc.scot.nhs.uk

April 2022