

The Value of Consumer Input - 'PROPEL' Trial

Anna Mamwell¹, Joanna Calder¹, Gillian Murphy¹, Elaine Stonock¹, Gillian Prue², Annie Young³, Laura Miller⁴, Simon Stanworth^{5,6}, Justin Loke⁷, Alice Longe³, Andrea Marshall³, Janet Dunn³,
on behalf of the PROPEL trial development group

¹PPI c/o Warwick Clinical Trials Unit, UK; ²School of Nursing and Midwifery, Queens University Belfast, UK; ³Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK; ⁴Nottingham University Hospitals NHS Trust; ⁵Department of Haematology, National Health Service and Transplant, Oxford University Hospitals NHS Trust, Oxford, UK; ⁶Radcliffe Department of Medicine, University of Oxford, UK; ⁷Centre for Clinical Haematology, Queen Elizabeth Hospital, Birmingham, UK;

ABSTRACT

Introduction: MASCC is promoting consumer engagement in supportive care; a recent MASCC survey showed that people affected by cancer are keen to contribute to research. The PROPEL trial is an example of how survivors of acute myeloid Leukaemia (AML) and their caregivers can successfully initiate and influence supportive care research. In our published scoping review of prehabilitation in haematological malignancies, no studies reported PPI in trial development.

Methods: Three survivors of AML and one caregiver from a UK national cancer research group were invited to a multiprofessional research steering group, having voiced their concerns at the lack of prehabilitation support for people with haematological malignancies. They developed and co-analysed i) a questionnaire to explore UK patients' and carers' experiences of prehabilitation for AML to shape the research; co-designed ii) a research funding application, and iii) the PROPEL protocol

Results:

- Patient advocacy was a continual thread with advocates included as applicants in the successful research funding. They, influenced:
 - Best practice usual care as the control arm as no prehabilitation arm was deemed as unacceptable.
 - The timing of first prehabilitation input in the experimental arm as post-induction treatment, as AML is often an emergency situation at diagnosis and the introduction at this stage was seen as inappropriate
 - The selection of fatigue as the optimal primary outcome measure. prehabilitation at home as an option as opposed to inpatient, as time spent at home was valuable
- This patient advocate-led questionnaire showed that prehabilitation is extremely important to people with AML and caregivers and there is a currently a lack of adequate NHS prehabilitation services.
- The patient advocates, contributed through their vast networks, mostly charities, to many sites participating in PROPEL.

Conclusions: The urgency of to establish the benefit of prehabilitation on fatigue, emotional wellbeing and quality of life, through research, was driven and successfully shaped by patient advocates.

INTRODUCTION

Acute myeloid leukaemia (AML) is the most common acute leukaemia, however 5-year survival in adults is around 20%. Treatment for AML requires multiple courses of intense chemotherapy, sometimes with stem cell transplant (SCT), which can result in debilitating fatigue, as well as poor appetite, muscle loss and low psychological wellbeing.

Prehabilitation (including supportive care interventions such as exercise, nutrition, psychological wellbeing) aims to improve general health and wellbeing, reduce fatigue and enable completion of AML treatments, which are critical for cure. There are a lack of prehabilitation services in the UK and uncertainty about effectiveness/cost-effectiveness of such programmes.

To inform the development of the PROPEL trial, a scoping review of supportive-care interventions delivered to adults with AML undergoing treatment (induction or consolidation chemotherapy, +/- SCT), was completed. No studies reported PPI involvement in trial development.

METHODS

Three survivors of AML and one caregiver (patient advocates) from a UK national cancer research group were invited to a multiprofessional research steering group, having voiced their concerns at the lack of prehabilitation support for people with haematological malignancies. Each PPI member has expansive networks of haematological cancer charities, research organisations in addition to their lived experience - to bring to the development, funding and implementation of this study.



They developed and co-analysed

- a questionnaire to explore UK patients' and carers' experiences of prehabilitation for AML to shape the research
- the research funding application
- the PROPEL protocol.

RESULTS

UK SURVEY

- 34 people with AML and 9 caregivers completed the questionnaire

PREHABILITATION IS EXTREMELY IMPORTANT TO PEOPLE WITH AML AND CAREGIVERS AND THERE IS A CURRENTLY A LACK OF ADEQUATE NHS PREHABILITATION

- Most respondents did not know the elements of prehabilitation
- 83% of people with AML stayed in hospital for treatment, presenting an opportunity for prehabilitation

COMPONENTS OF PREHAB:

- 45% had been offered nutritional support by a dietitian - two thirds of whom found the support helpful
- Only 25% were aware of or offered any additional support for physical exercise – none of these said it wasn't helpful
- 60% had received additional psychological support, mostly from cancer charities



What the patients said about PROPEL design:

A best practice usual care must be introduced – a 'no intervention' arm is unacceptable

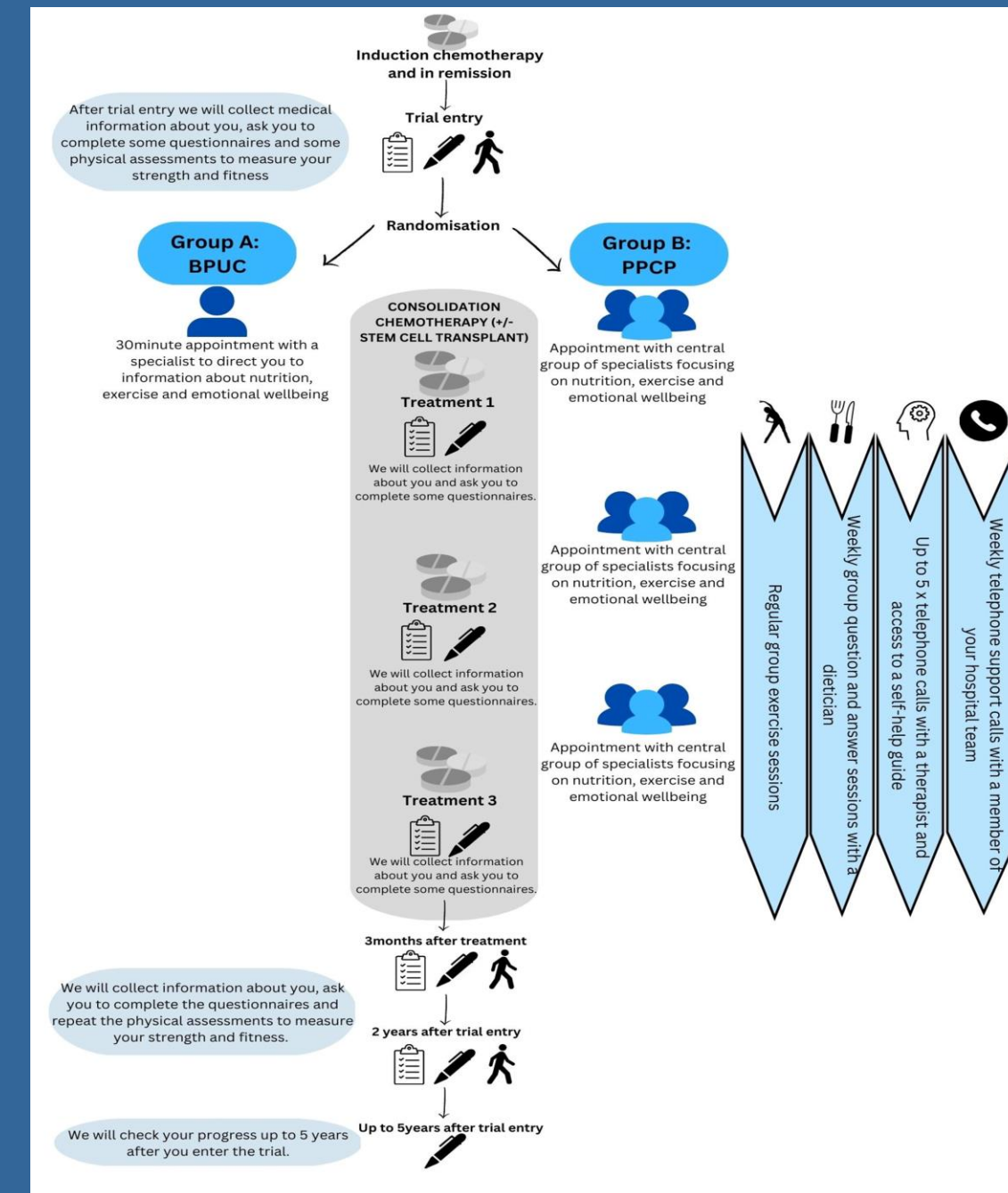
Inappropriate to try and introduce prehab prior to induction chemotherapy, this is an emergency situation

The primary outcome measure must be something that is of importance to PATIENTS – suggest using fatigue

Prehab must be able to be offered at home as well as an inpatient. Time spent at home is invaluable

THE PROPEL TRIAL PROTOCOL

Changes in protocol due to PPI input included timing of the intervention and timing of the assessments to simplify the pathway:



BPUC – Best Practice Usual Care;
PPCP – Personalised Prehabilitation Care Plan

CONCLUSIONS

- PROPEL has benefitted enormously from patient engagement throughout the design, funding and protocol - confirming the outcomes and refining the intervention
- Consumer involvement has confirmed the need for the trial and the importance of an active control arm
- The consumers will continue to have an active role throughout the PROPEL trial as equal partners in the trial team, ultimately to find out the clinical impact and cost-effectiveness of BPUC compared to PPCP on fatigue, emotional wellbeing, and quality of life (QoL) – in patients receiving remission consolidation treatment for AML or high-risk myelodysplastic syndromes with excess blasts (MDS-EB2)

For more information, please contact PROPEL@warwick.ac.uk

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