Patient-reported outcomes in multiple myeloma: real-time reporting to improve care

(Methodology of the My-PROMPT study)

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Background

In Australia, despite improvements in diagnosis and care, only 49% of patients diagnosed with multiple myeloma (MM) are alive at five years. MM is incurable, is associated with a high burden of disease, and >1600 new cases are diagnosed in Australia each year.

Although improved overall survival remains a major goal of cancer treatment, health-related quality of life (HRQOL) is increasingly important to patients and clinicians. However, few data exist on optimal measures to improve QOL in patients with MM. HRQOL is incorporated in patient-reported outcomes (PROs). Involving patients in their care by feeding back PROs to clinicians could enhance QOL and warrants investigation.

Methods

PROs: individuals' assessments of their own health & wellbeing. PROs can help in making patient-centred treatment decisions, and in understanding overall treatment effectiveness and patient priorities.

The MyPOS questionnaire was chosen to collect PROs in this study. It is myeloma-specific, designed for use in the clinical setting, and validated in MM.

Design

•My-PROMPT is a substudy of the Myeloma and Related Diseases Registry (MRDR) – it leverages registry infrastructure and recruitment to facilitate completion.

•Multicentre pilot randomised trial to test the feasibility of real-time reporting of PROs to clinicians.

•Target: 30 patients – newly diagnosed MM, MRDR participants, ≥18 years, within 7 days of starting first treatment.

•Primary aim: assess feasibility of real-time reporting of PROs.

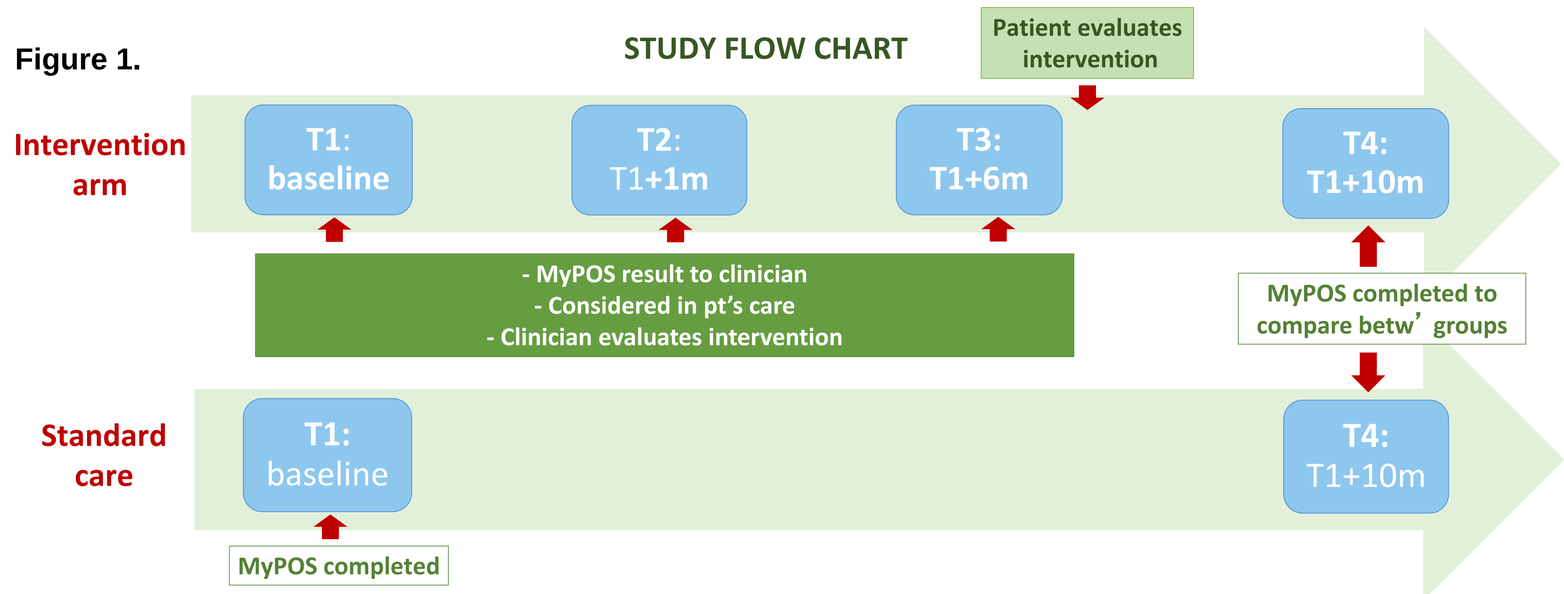
•Secondary aim: assess benefit of intervention on HRQOL.

Intervention arm: patients complete MyPOS before 4 clinical visits: baseline (close to diagnosis) and then at 1, 6 & 10 months. Treating clinicians are given a summary of MyPOS results before visits and encouraged to use this in patients' care (see Figure 1 & 2).

Patients and clinicians complete surveys on the intervention to assess feasibility for wider use (Figure 2).

Standard care arm: patients complete MyPOS only at baseline and 10 months to compare change in HRQOL from baseline between groups (Figure 1).

Figure 1.



Evaluations: patient & clinician

Questions cover: MyPOS questionnaire content, impact on the consultation, and frequency of visits.

Additional information:

- Patient evaluations: ease of completion, time taken
- Clinician evaluations: timeliness in receiving MyPOS summary, workload impact, actions (e.g. referrals)

Study status

- Funding and ethics approval obtained.
- MyPOS is incorporated in the MRDR platform
  - Completion online / via tablet in clinic
  - MyPOS summary generated in real time
  - Workflow reminders for pending visits
- Recruitment is in progress - 4 sites.

Significance

•Consumers, clinicians, health services, government, insurers and industry recognise the potential value of PROs (particulary in long-term, high burden disease).

•PROs / pt-centred care are increasingly important in policy and practice:

- Victorian Agency for Health Information plan to collect PRO data.
- Cancer Institute NSW: PRO initiative – a key priority of the Cancer Plan.

•If the study intervention is shown to be feasible, we will consider a larger study to assess the impact on HRQOL.

•Results should be readily translatable to other cancers and patient groups.

MRDR: the context for My-PROMPT

The intention of the MRDR is to support a range of research studies. This is the first study of this kind conducted by the registry.

The MRDR is well-placed to provide a framework for projects:

- The Australia/New Zealand site and investigator network is established and >1700 patients have already been recruited.
- The Myeloma 1000 blood biobank substudy, collecting samples from patients with MM & MGUS, is underway.
- Several early phase clinical trials of frontline therapy are in progress or in development.
- The MRDR continues to expand. New site participation & research proposals are very welcome.

Contact us

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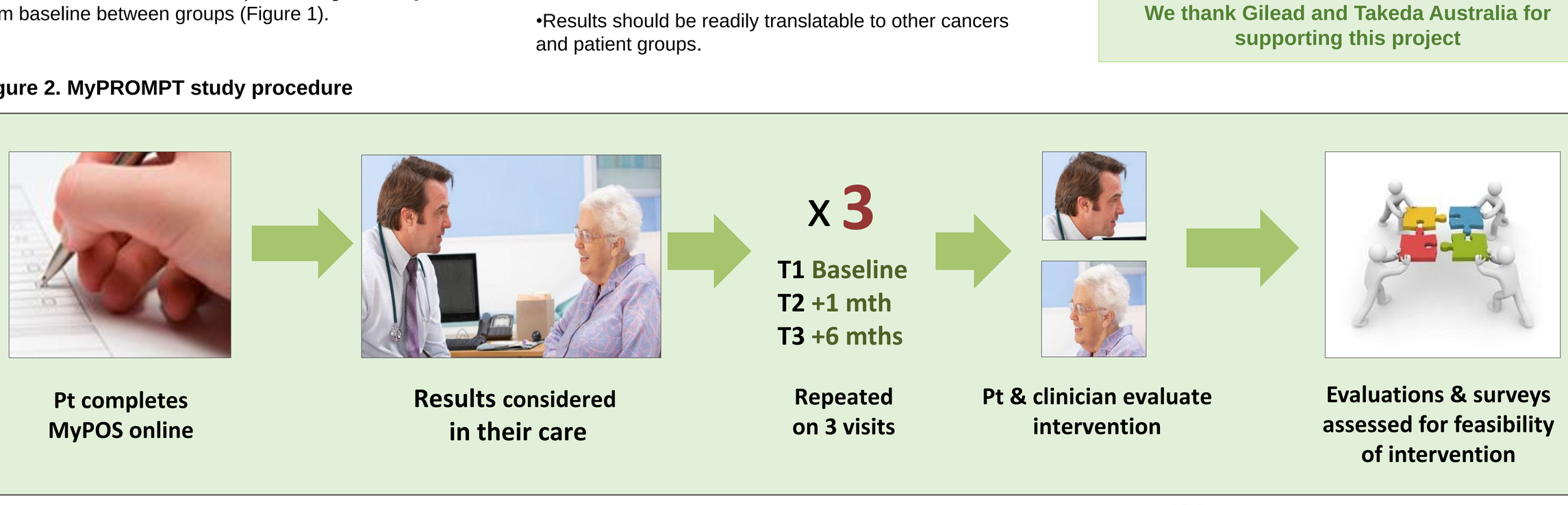
Figure 2. MyPROMPT study procedure



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