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ORIGINAL RESEARCH ARTICLE

Practical considerations towards the collection of patient reported outcome data among hematopoietic cell transplant recipients

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Abstract

Background There is increasing interest in using patient-reported outcome measures (PROMs) to assess quality of life (QoL) following hematopoietic cell transplant (HCT). However, there is limited consensus on how such data should be collected within HCT services. This survey study investigated health professionals (HCPs) views towards QoL data collection and factors affecting the use of PROMs within HCT centres in the UK.

Method Individual survey items were based upon the Consolidated Framework for Implementation Research (CFIR). The CFIR consists of five domains which are known to affect intervention (in this instance PROM) adoption and implementation. National coverage was achieved with survey responses received from all UK adult allograft HCT centres.

Results Findings indicated PROMs use in UK HCT services is ad hoc with PROMs mostly used as screening or diagnostic tools for emotional health or for service improvement activities including audits. HCPs reported that patient-reported outcome (PRO) data collection is limited by a lack of resource, infrastructure and referral pathways if the PROM were to flag a patient issue. A large proportion of HCPs (> 70%) noted that PRO data within their centre would be best enabled through dedicated research staff and data management infrastructure to support data collection and storage. Despite growing evidence of the utility of electronic data capture, most HCPs (> 50%) believed electronic PROMs (ePROMs) may be difficult to implement due to data protection issues and limited access to electronic devices.

Conclusions These findings highlight the opportunities and challenges to PRO data collection in UK HCT services and demonstrate the need for practical solutions. The development of a standardised approach to PROM use among HCT recipients and investment in workforce and data management infrastructure is needed to support an integrated approach to PRO data collection, storage and use.

1 Introduction

In the United Kingdom (UK), patient-reported outcome (PRO) data collection is mandated and centrally co-ordinated for patients undergoing elective surgery for hip or knee replacement, varicose veins and hernia repair [1]. The PRO data gathered in these settings has provided a wealth of information about patient well-being post-operation and the surgical performance of individual National Health Service (NHS) trusts. However, beyond mandated use for specific surgical procedures, anecdotal evidence suggests PRO data collection across other services within the NHS is fragmented and ad hoc [2, 3].

As outlined by the UK Stem Cell Strategic Forum (UKSCSF) 10-year Vision published in 2022, there is a need to collect self-reported experience and quality of life data among patients receiving hematopoietic stem cell transplant (HCT) [4]. Such data, collected using patient-reported outcome measures (PROMs), would allow insight into patients' experience of receiving a HCT, including the effect of HCT upon patient mobility, emotional well-being, social function and symptom burden [5, 6]. PRO data could also enable healthcare teams to audit clinical performance and facilitate care management through shared decision-making between patients and clinicians prompted by real-time feedback of symptom burden and patient function [6].

Despite ambitions to increase PRO data collection in the NHS, a number of barriers to PROMs implementation have been identified, including capacity, clinician perception of the patient benefit, organisational resource availability, administrative support and existing workflows [8]. Facilitators to PRO data collection include the perceived relevance of the measure to patients, real-time feedback

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Key Points for Decision Makers

HCPs reported that PRO data collection is limited by a lack of resource and infrastructure. Particularly, HCPs cited limited referral pathways if the PROM were to flag a patient issue which required support or follow-up.

While most HCPs believed PRO data collection should be digital, many thought ePROMs would be difficult to implement due to data protection issues and limited access to electronic devices. This is despite increasing evidence demonstrating the potential utility of ePROMs.

The development of a standardised approach to PROM use among recipients of HCT and investment in workforce and data management infrastructure are needed to support an integrated approach to PRO data collection, storage and use.

of PROMs score to clinicians to aid decision-making and organisational support and staff training to use PROMs [1, 7, 8].

At present, there is a limited insight guiding understanding about how PROMs could be integrated into routine clinical care and data collection in UK HCT services. Within a wider programme of research which aims to scale the collection of socioeconomic and quality of life data, the purpose of this study was to assess the knowledge, use and attitudes of health professionals (HCPs) towards PROMs and identify enablers and barriers to the routine collection of PRO data in HCT services across the UK.

2 Methods

2.1 Study Design

To identify the current use of PROMs and evaluate barriers and enablers to the routine collection of PRO data in the HCT setting an online questionnaire was disseminated to health professionals who work within HCT services. Similar studies exploring professionals' attitudes to PROM data collection in the primary care and radiography setting have previously been conducted [2, 9].

2.2 Population

All health professionals working in a HCT setting, including clinicians, nurses, allied health professionals and service managers were eligible to participate within this study.

2.3 Recruitment and Sample Size

Snowball sampling was carried out with the aim of recruiting a minimum of one person per HCT centre. Convenience sampling was also used, and HCPs who were on Anthony Nolan mailing lists were contacted and asked to complete the survey and share it among colleagues. The questionnaire remained open for a period of 8 weeks, and survey reminders email were sent periodically prior to closure.

2.4 Data Collection

Questionnaire items were based upon previous research exploring the use of PROMs in the primary care setting and Italian comprehensive cancer centres [8]. Individual survey items exploring HCPs' opinions about PROMs and barriers and enablers to PROMs data collection were based upon the Consolidated Framework for Implementation Research (CFIR). The CFIR consists of five domains which are known to affect the adoption and implementation of an intervention (in this instance PROMs). The CFIR has previously been used to classify barriers and facilitators to PROMs implementation across health-related services [10].

The final questionnaire [Online Supplementary Material (OSM) File 1] was piloted by the Anthony Nolan lead nurse (R.M.), chief medical and scientific officer (R.D.) and two clinical psychologists before being disseminated.

HCPs were asked to report data on their professional role, hospital affiliation and years of experience working with patients who have undergone HCT.

HCPs were asked to review a list of common PROM tools and asked to identify whether they were aware of the tool and had experience using it. A single yes/no question was used to investigate the use of non-validated tools and the use of other tools not included in the original list. HCPs were asked whether they use PROMs as part of standard care, in clinical research or for quality and service improvement monitoring. If HCPs used PROMs as part of standard care, they were asked to select the purpose and identify whether PRO data are used for triage, screening, diagnostics, facilitation of communication or personalised care planning. Data on how (format) and when PROMs are completed was captured using multiple response questions. Data on who collects and analyses PRO data were collected in a similar format.

HCPs were asked a single multiple-choice question about who they thought was best to recruit patients to complete PROMs and who should have the responsibility of reviewing and discussing outcome data with patients. HCPs were asked to report when they thought the best time for PRO data collection was, choosing from during transplant workup, at transplant enrolment, during acute transplant care and

during long-term follow-up. A list of statements about benefits (strengths) and drawbacks (weaknesses) of PRO data collection were provided to gather HCPs' opinion about patient-reported data collection. These items are based upon survey items used with a previous study exploring HCPs perspectives of PROMs use in Italy [11].

HCPs were asked to rank the extent to which they think known facilitators of PROMs use would influence PRO data collection within their centre. The items contained within the list were based upon the CFIR.

2.5 Statistical Analysis

To ensure data quality and eliminate poor data from analysis, a quality check of survey responses was performed before analysis. When a participant started but did not complete the survey, available responses were included in analysis. Survey responses were aggregated and reported using descriptive statistics. Frequency distributions were used to describe respondent characteristics and survey responses. Due to the small sample, exploratory logistic regressions analysis was not used to investigate differences in PROMs use between professional groups (e.g. clinicians, nurses and allied health professionals).

3 Results

A total of 105 health professionals followed the survey link, 44 provided only demographic information and were excluded from the analysis, 16 provided partial responses and 45 provided answers to all survey questions. Both partial and complete responses (total $n = 61$) were included within the analysis**.** The missing responses were at random throughout the survey, aside from the final section related to barriers and facilitators, which had a markedly lower response rate ($n = 46$ total responses) compared with the other sections, with response rates ranging from $n = 53$ to $n = 61$.

The characteristics of survey respondents are displayed in Table 1. The majority of participants were nurses, working with both autologous and allograft patients and had been working with transplant recipients for more than 10 years. The majority of HCPs were involved in local audit activities ($n = 51$, 84%), and most were involved in clinical trial research ($n = 31$, 51%).

Of the respondents, 63% ($n = 38$) reported using PROMs as part of standard care or clinical practice. The most common uses of PROMs were as screening or diagnostic tools for emotional health ($n = 31$, 52%); for quality improvement activities, including audits ($n = 29$, 48%); and in clinical trials and research ($n = 26$, 43%). Of respondents, 20% ($n = 12$) reported not using PROMs.

Figure 1 presents data on the knowledge and use of PROMs commonly used in the cancer and blood and marrow transplant (BMT) literature. The majority (> 55%) of health professionals were unaware of common PROMs. The most known PROMs (respondents recognised or had previous experience using them) were the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30; $n = 26$, 43%) and Hospital Anxiety and Depression Scale ($n = 25$, 42%). The most frequently used PROMs in current practice were the Functional Assessment of Cancer Therapy – Bone Marrow Transplantation (FACT-BMT; $n = 19$, 31%) and Patient-Reported Outcomes Measurement Information System (PROMIS) tools ($n = 6$, 10%). Sub-analysis of respondents who reported working in the paediatric setting ($n = 12$) indicated that the Pediatric Quality of Life Inventory (PedsQL) was the most commonly known and used PROM ($n = 7$, 58%).

Of the HCPs surveyed, 28% ($n = 17$) stated that they currently use other PROMs within their service. The other PROMS used included the Public Health Questionnaire-9 (PHQ-9), Generalised Anxiety Disorder Assessment (GAD-7) and local holistic needs assessments.

Paper-based data collection was most common with 82% ($n = 42$) of respondents reporting data collection via this method. Interviews to collect data in person ($n = 19$, 37%) and over the phone ($n = 14$, 27%) were the second most common data collection methods. Very few (< 25%) reported using digital surveys via website or app-based platforms.

The majority of HCPs reported that PRO data are collected at multiple timepoints within their HCT centre. The most common timepoint of PRO data collection was during post-transplant follow-up either 3+ months post-transplant ($n = 34$, 67%) or 1+ years ($n = 33$, 65%). During transplant in-patient or ambulatory care (up to day 28) was the least common timepoint for PRO data collection ($n = 17$, 33%). Open responses indicated that timing of PRO data collection 'depends on patients pathway post transplant' and often 'dictated by clinical trial requirements'. Two respondents noted that PRO data are collected pre- and post-counselling therapy in their centre, and one respondent noted that chronic graft-versus-host-disease (GVHD) data are routinely collected by the apheresis team for patients receiving extracorporeal photopheresis (ECP) in their service.

Most HCPs surveyed thought PRO data should be collected electronically online ($n = 17$, 30%) or through an app ($n = 8$, 14%). Meanwhile, 48% ($n = 28$) believed a nurse should be available to review PRO data and discuss individual responses or results with patients.

Figure 2 outlines HCPs views about PRO data collection. HCPs who participated within the survey reported strong positive beliefs about the benefits of PROMs in supporting

Table 1 Participant characteristics & patient-reported outcome data collection practices

	$N = 61$ (100%)
Type of centre	
Adult	44
Paediatric	12
Both	5
Transplants available within service	
Auto only	7
Auto and Allograft	54
Profession	
Nurse	30
Clinician	11
Psychologist	7
Occupational therapist	1
Physiotherapist	5
Other	8
Average length of time working with transplant recipients	
< 1 year	7
2–5 years	12
6–10 years	6
10+ years	36
Clinical trial research	
Yes	19
Quality or service improvements including audits	
Yes	51
Current method of PRO data collection	$n = 50$
Paper	42
Online via website	11
Mobile app	4
Interview in person	19
Interview on the phone	14
Proxy (completed on behalf of the patient by professional)	4
Other	0
Current timing of PRO data collection	$n = 52$
During transplant work up	25
During transplant in-patient/ambulatory care (up to day 28)	17
During early post transplant care (1–3 months post transplant)	26
During continuous follow-up (3 months–1 year)	34
During long-term follow-up post-transplant (1 year + post transplant)	33
Other	7
Person collecting PRO data at centre	$n = 51$
Clinician	2
Data Manager	8
Multiple professionals	16
Nurse	16
Occupational therapist	2
Other	1
Physiotherapist	1
Psychologist	5

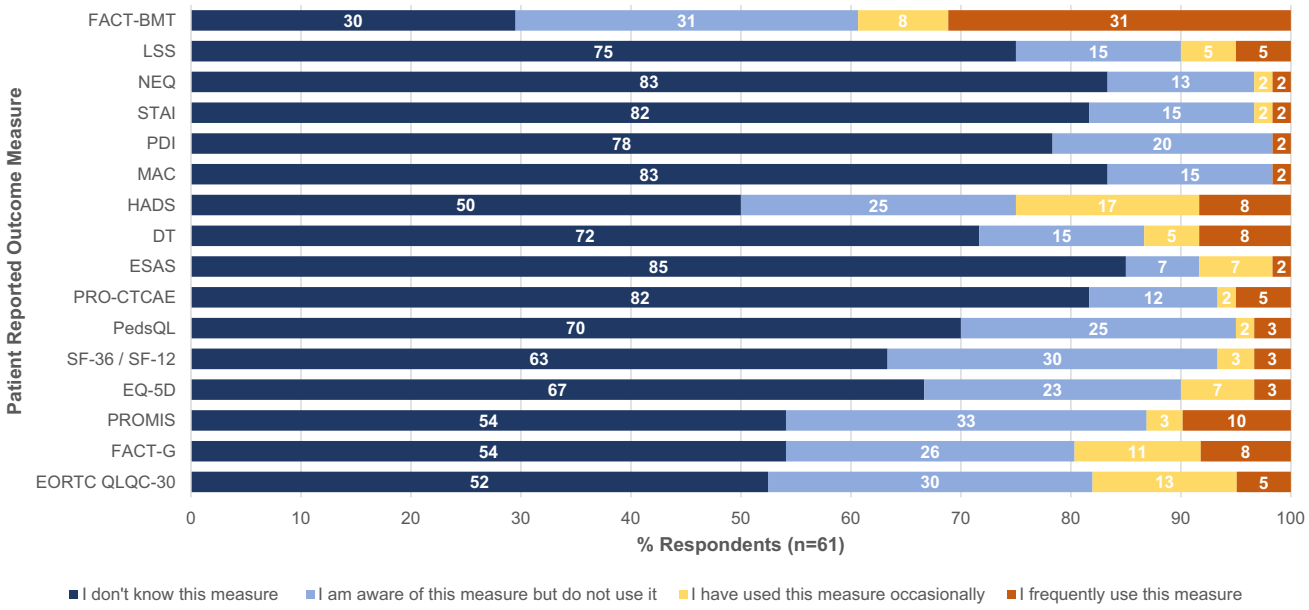

Fig. 1 Health professionals' knowledge and use of common PROMs. *FACT-BMT* Functional Assessment of Cancer Therapy-Bone Marrow Transplantation, *LSS* Lee Symptom Scale, *NEQ* Needs Evaluation Questionnaire, *STAI* State-Trait Anxiety Inventory, *PDI* Psychological Distress Inventory, *MAC* Mental Adjustment to Cancer, *HADS* Hospital Anxiety Depression Scale, *DT* Distress Thermometer, *ESAS* Edmonton Symptom Assessment Scale, *PRO-CTCAE*, Patient-Reported Outcome Common Terminology Criteria for Adverse Events, *PROMIS* Patient-Reported Outcomes Measurement Information System, *FACT-G* Functional Assessment of Cancer Therapy-General, *EORTC QLQC-30* European Organisation Research and Treatment of Cancer Core Quality of Life Questionnaire

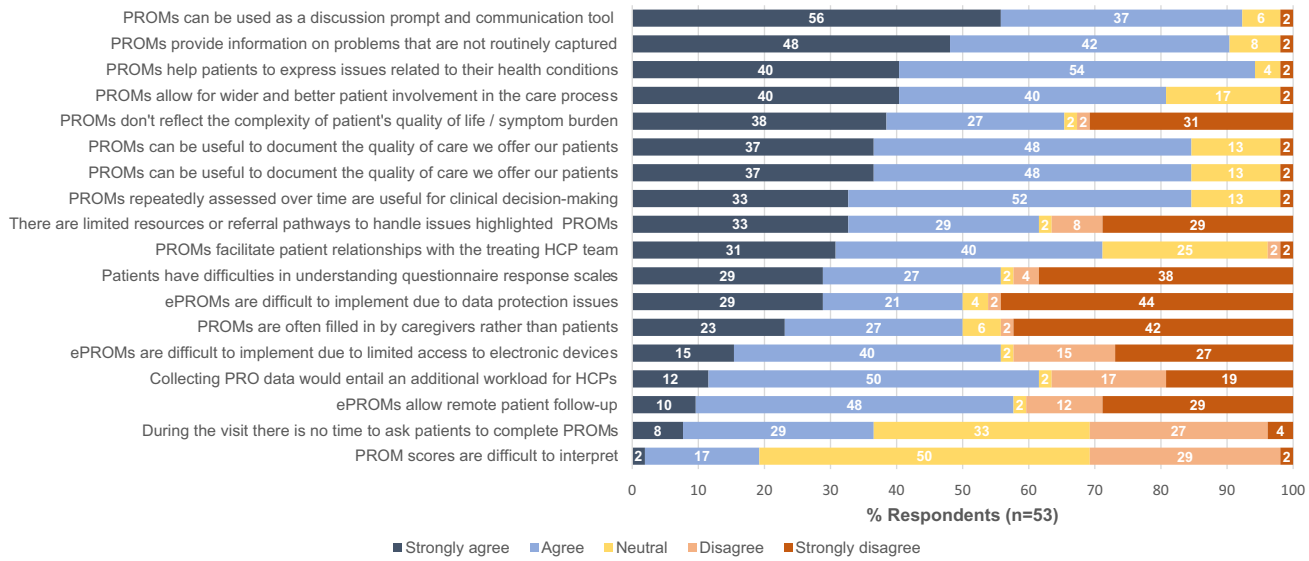

Fig. 2 Health professionals' views about PRO data collection

patient care. Over 80% of HCPs strongly agreed/agreed that PROMs can be used as discussion prompts and communications tools, provide information that is not routinely captured and help patients express issues related to their health condition that might not otherwise be raised. However, it was evident that HCPs ability to collect PRO data is often limited by resource, infrastructure and an absence of referral pathways if the PRO data collected was to suggest a patient may benefit from further support. Many HCPs (> 50%) indicated that patients have difficulty understanding questionnaire response scales, that PROMs do not reflect the complexity of the symptom burden of patients who have

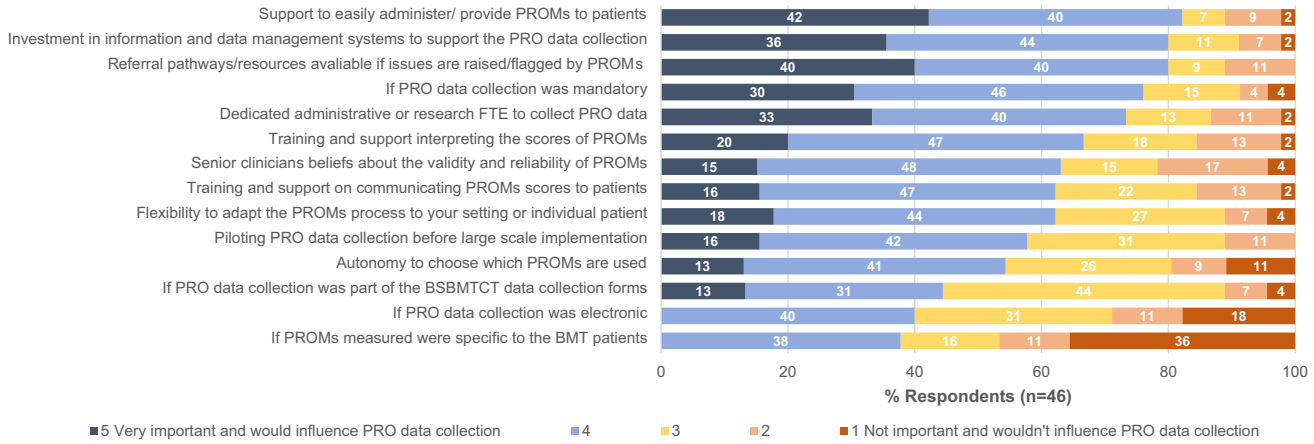

Fig. 3 Health professionals' views about facilitators of PRO data collection

received HCT and that collecting PRO data would entail an additional workload for staff. Although some HCPs (n = 30; 41%) viewed electronic collection of PROMs (ePROMs) as useful to allow remote patient follow-up, many (> 50%) believed ePROMs may be difficult to implement due to data protection issues and limited access to electronic devices.

Figure 3 outlines facilitators to PRO data collection. Support to administer PROMs to patients and investment in information technology (IT) and data management systems to support PRO data collection were viewed as the most important facilitators to aid future PRO data collection. Specifically dedicated administrative or research time for staff to collect PRO data and training to interpret the scores of PROMs were viewed to influence PRO data collection. More than 60% of HCPs believed senior clinicians' beliefs about the validity and reliability of PROMs would influence PRO data collection within their centre.

4 Discussion

This study demonstrated that HCPs value the benefit of embedding PROMs into routine practice to monitor the impact of HCT on patient well-being and enhance communication with patients and families. However, the need for infrastructure and resource to operationally support PRO data collection was evident.

A large proportion of HCPs believed routine PRO data collection would improve patient–clinician communication and highlight patient issues which may otherwise go undetected. These findings are reflective of existing evidence that the use of patient-derived data is associated with higher quality of care and patient satisfaction [3, 5, 7]. Reassuringly, unlike within other studies, within this study there was no evidence that HCPs are sceptical about whether PROMs truly make a difference to patient outcomes. However, > 50% of HCPs did report that senior clinicians' beliefs about the validity and reliability of PROMs would influence data collection within their centre. Ambiguity about the use of PROMs is known to affect routine collection of PRO data [8]. Successful implementation and use of PROMs is dependent upon clinical engagement and workflow integration. Specifically senior clinician buy-in about PRO data being useful to personalise care could facilitate the adoption of PROMs in routine care. As reflected by findings within this study, any developments towards integrating data collection into workflow should also consider downstream referral pathways if a PROM identifies a patient issue.

HCPs views regarding barriers to PRO data collection aligned with key themes previously identified within the literature [11, 12]. Overall, it was clear that PRO data collection in the UK HCT setting would be best facilitated by operational support including dedicated administrative or research staff to facilitate PRO data collection. In the UK there are several policy initiatives underway designed to improve general access and availability of health outcome data for patient benefit [12, 13]. This includes strategic goals set out by the UKSCSF to create a new integrated model for UK HCT and cellular therapies data [4]. Any strategic investment in HCT data collection should include resources to facilitate and support PRO data collection alongside traditional clinical outcome measures such as survival, mortality and morbidity. This requires digital infrastructure that enables data interoperability. In this study, 44% of HCPs felt integrating PRO data collection with routine British Society of Bone Marrow Transplant and Cellular Therapies (BSBMTCT) registry would be beneficial. The Centre for International Blood and Marrow Transplant Research (CIBMTR) has demonstrated that a hybrid model of local consent and PRO data collection linked to centrally collected clinical outcomes data is feasible [14]. Open architecture approaches based on principles of interoperability and data

standards would enable data to be captured and used multiple times across different systems and contexts. However, this approach is dependent on standardised and consistent approaches to data collection across multiple platforms and organisations.

Within this study HCPs reported PROMs were mostly used as screening or diagnostic tools for emotional health; for service improvement activities, including audits; and in clinical trials and research. While there is debate about which PROMs should be used among patients who have received HCT, there is consensus that the PROMs used should measure domains and constructs most relevant to patients [3, 8, 9]. As such, it was encouraging that there was a reasonable level of familiarity among HCPs with both condition-specific measures such as the FACT-BMT and generic measures such as the PROMIS. The development of a standardised approach to PRO data collection among recipients of HCT would improve the comparability and use of PRO data beyond the needs of single studies or clinical settings [15].

Unsurprisingly, paper-based PRO data collection was most common in current practice. HCPs believed ePROMs would be difficult to implement due to data protection and limited patient access to electronic devices such as a smartphone or computer. HCPs beliefs contrast with increasing evidence that ePROMs are acceptable to patients and are less burdensome for patients to complete [16]. While paper PROMs should continue to be available to patients who prefer or require their use, the use of ePROMs among patients who have received HCT should be encouraged, as the collection of PRO data using electronic devices would reduce administrative burden for HCPs and enhance the likelihood of PRO data being integrated with other health data. Both patients and HCPs should be provided with support to use ePROMs.

4.1 Strengths and Limitations

Although this study provides valuable insight on HCPs' views towards patient-reported outcome data collection and the factors affecting the use of PROMs within HCT centres in the UK, there are several limitations. Firstly, snowball and convenience sampling were used to recruit potential participants. While a response was received from every HCT centre in the UK which undertakes allograft transplants, it is likely that respondents were HCPs who were engaged with Anthony Nolan or engaged in PRO data collection. This may limit the generalisability of the results. In addition, while the sample size was sufficient to provide a reasonable representation of HCT professionals covering all allograft HCT centres, formal statistical analyses comparing professional groups viewpoints or differences in practice between clinical settings, geographical regions or patient populations was not possible. Further research involving a larger sample of the HCT workforce is needed to confirm the broader application of the findings. Nevertheless, this study provides important insight on the current capacity for PRO data collection in the UK HCT setting.

5 Conclusions and Recommendations

The findings from this study demonstrate that the potential benefits of PRO data collection are recognised by HCPs working with HCT recipients. The barriers to PRO data collection identified within this study reflect environment- and process-related factors known to influence PRO data collection in other clinical specialities. The development of a standardised approach to PROM use among recipients of HCT and investment in workforce and data management infrastructure is needed to prevent fragmented and ad hoc PRO data collection in the UK HCT setting.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s40271-025-00769-z.

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Declarations

Conflict of Interest All authors are employees of Anthony Nolan.

Data Availability Statement The datasets generated during this current study are available from the corresponding author on reasonable request.

Author Contributions G.P.: conceptualisation and design, formal analysis and methodology, writing of the original draft and reviewing and editing of the final draft. C.Y.: data curation and reviewing and editing of the final draft. D.H.: conceptualisation and design and reviewing and editing of the final draft. R.M.: conceptualisation and design and reviewing and editing of the final draft. R.D.: conceptualisation and design and reviewing and editing of the final draft.

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