

Patient and carer access to medicines at end of life: the ActMed mixed-methods study

Sue Latter,^{1*} Natasha Campling,¹ Jacqueline Birtwistle,² Alison Richardson,^{1,3} Michael I Bennett,² David Meads,⁴ Alison Blenkinsopp,⁵ Liz Breen,⁵ Zoe Edwards,² Claire Sloan,⁴ Elizabeth Miller,^{6,7} Sean Ewings,⁸ Miriam Santer⁹ and Lesley Roberts¹⁰

¹School of Health Sciences, University of Southampton, Southampton, UK

²Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

³University Hospital Southampton NHS Foundation Trust, Southampton, UK

⁴Academic Unit of Health Economics, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

⁵School of Pharmacy and Medical Sciences, University of Bradford, Bradford, UK

⁶Pharmacy, St Luke's Hospice, Sheffield, UK

⁷Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

⁸Faculty of Medicine, University of Southampton, Southampton, UK

⁹School of Primary Care, Population Sciences and Medical Education, University of Southampton, Southampton, UK

¹⁰Patient and public involvement representative, Staffordshire, UK

*Corresponding author S.M.Latter@soton.ac.uk

Declared competing interests of authors: Alison Richardson reports secondment to NHS England (London, UK) as Head of Nursing Research (Academic Leadership & Strategy) and grants from the National Institute for Health and Care Research outside the submitted work.

Published July 2022

DOI: 10.3310/FIQE5189

Scientific summary

The ActMed mixed-methods study

Health and Social Care Delivery Research 2022; Vol. 10: No. 20

DOI: 10.3310/FIQE5189

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

Patient and carer access to medicines during the last 12 months of life [i.e. end of life (EoL)] is critical for controlling symptoms, including pain and distress, and for reducing the urgent and unplanned use of health-care services. However, data from our previous studies [Latter S, Hopkinson J, Richardson A, Lowson E, Hughes J, Hughes J, *et al.* *A Phase I-II Feasibility Trial of Cancer Carer Medicines Management (CCMM): An Educational Intervention for Carer Management of Pain Medication in Cancer Patients at End of Life. Final Report.* London: Marie Curie; 2015. Bennett MI, Mulvey MR, Campling N, Latter S, Richardson A, Bekker H, *et al.* Self-management toolkit and delivery strategy for end-of-life pain: the mixed-methods feasibility study. *Health Technol Assess* 2017;**21**(76)] suggested that prescription, dispensing, supply and associated information given about medicines are often considered difficult, demanding, lacking co-ordination and involving a multiplicity of professionals by patients using these services. Although evidence is suggestive of problems with patient and carer access to traditional service delivery systems, including general practitioner (GP) care, little is known about this. In addition, there are indications that critical sectors of the EoL workforce [i.e. palliative care nurse specialists and community pharmacists (CPs)] are currently underutilised. Little is known about why sectors in this area remain underutilised and evidence about their impact on patient experience of medicines access is lacking. Furthermore, although there are promising innovations in EoL care models, the impact of these innovations on patient access to medicines, as well as their cost-effectiveness comparative to more traditional delivery models, remains largely unevaluated. Our recent research also suggests that the supply chain 'upstream' may be a contributing factor to the complexity and problems with access experienced by patients. However, to our knowledge, CP, wholesaler and distributor perspectives on the supply chain of EoL medicines has not been investigated.

Aims and objectives

We aimed to provide an evaluation of patient and carer access to medicines at EoL within the context of models of service delivery.

Objectives

- To produce a critical overview of existing research on experiences and outcomes of medicines access within EoL models of service delivery through a systematic literature review (phase 1).
- To undertake a large-scale survey to evaluate EoL care professionals' current practices, as well as:
 - identify factors influencing professionals' contributions
 - assess the potential of the community-based nurse and pharmacist workforce to improve patient access to medicines at EoL
 - provide an overview of current models of service delivery (phase 2).
- To evaluate and compare patient and carer experience of medicines access within models of EoL service delivery, including those featuring innovations in care, through undertaking mixed-methods case studies of practice (phase 3).
- To estimate the cost-effectiveness of service models (phase 3).
- To map patient 'access to medicines pathways' at EoL, including timelines of problems, decisions, actions and use of services (phase 3).

- To identify barriers to and facilitators of maximising the contribution of the nurse and pharmacist workforce to medicines access at EoL (phases 2 and 3).
- To interview CPs, wholesalers and distributors to evaluate supply chain processes and identify challenges in providing access to EoL medicines (phase 4).
- To convene an expert consensus-building workshop to review study findings and generate recommendations on key characteristics of EoL service delivery that support medicines access (phase 5).

Methods

The study used a multiphase mixed-methods design with sequential linked phases, by which initial phases informed subsequent phases.

Phase 1

Phase 1 comprised a systematic literature review using systematic searches of MEDLINE, Cumulative Index to Nursing and Allied Health Literature, EMBASE, PsycInfo® (searched for published literature from January 2006 to March 2019), Cochrane Library databases and grey literature (literature published from January 2006 to June 2019). Databases were systematically searched for all types of studies. Study quality was assessed using the mixed-method appraisal tool and a narrative synthesis was used to integrate and summarise findings.

Phase 2

Phase 2 comprised an online questionnaire survey of health-care professionals (HCPs) [i.e. GPs, CPs, community-based clinical nurse specialists (CNSs) and community nurses (CNs)] delivering EoL care in primary and community care settings in England. We aimed to achieve 200 responses from each professional group. The survey was distributed by e-mail via Clinical Research Networks (CRNs), community trusts and hospice clinical leads in England. It was also advertised online and on websites via a number of national EoL professional organisations. Quantitative data were analysed using descriptive statistics. A directed content analysis approach was undertaken to analyse free-text responses, including quantification.

Phase 3

Phase 3 involved mixed-methods case studies of four service delivery models: (1) GPs, (2) CNS prescribers, (3) community pharmacy-commissioned palliative medicines services and (4) a 24 hours per day, 7 days per week telephone support line (TSL). Within cases 1, 2 and 4, we purposively sampled up to 10 patients and their carers. These patients and their carers completed logs of medicines access experiences and took part in up to three interviews at study entry, 4 weeks and 8 weeks. In these case sites, we also extracted data on prescribed medicines and health-care resource use from up to 40 patient records and interviewed a purposive sample of HCPs who provided EoL care. Detailed contextual data on each case were also collected from a range of documents. In case 3, interviews were conducted with CPs who provided commissioned services, commissioners of these services and EoL HCPs. Pharmacists were purposively sampled from phase 2 and phase 4 participants, as well as CRNs and research team networks. Commissioner interviewees were identified using snowballing from CPs and publicly available data on Clinical Commissioning Group and NHS England websites. Nested sampling occurred. EoL HCPs, interviewed within sites 1, 2 and 4, were asked for their views on community pharmacy-commissioned medicines services. A documentary analysis on commissioned services' documents was also undertaken.

Logic models were used to summarise case characteristics, their mechanisms of action, mediating and moderating factors and outcomes for each site, as well as a cross-case comparison of medicines access experiences.

For each case, we costed the prescription services and estimated the overall budget impact of these. We used patient records to estimate resource use costs for three of the case sites and estimate the probability of unplanned hospital/hospice use for symptom management. We used these estimates and an adapted decision model to estimate cost-effectiveness, using the GP service as usual care.

Phase 4

In phase 4, interviews with CPs and pharmaceutical WDs were conducted. Purposive sampling through CRNs, respondents in phase 2 and snowball sampling was used to identify pharmacists. Wholesalers and distributors were recruited via both the trade association and snowball sampling. All interview data were analysed using framework analysis.

Phase 5

In phase 5, an expert workshop was held to discuss study findings and generate implications. Participants were purposively sampled for their expertise in EoL practice, service delivery, policy or research. Sampling was through research team networks, including snowball sampling.

Findings

Phase 1

The quantity and quality of evidence was very limited. Ten studies were included in the review. The majority of studies consisted of small local samples, largely limited to self-reports of HCPs. Community pharmacy services were characterised by access delays. Hospice emergency medication kits in the USA were perceived to reduce medicines' access time out of hours (OOH) and speed symptom control. There was a lack of data on outcomes and there were no comparisons between service delivery models, highlighting that further research was needed in this area.

Phase 2

A total of 1327 responses were received (GPs, $n = 499$; CNSs, $n = 389$; CPs, $n = 219$; primary care pharmacists, $n = 151$; CNs, $n = 99$). Results showed that although GPs remain a predominant route for patients to access new prescriptions, nurses and, increasingly, primary care-based pharmacists are also actively contributing. However, only 41% (160/386) of CNSs and 27% (27/99) of CNs were trained as prescribers. The majority (142/244, 58%) of prescribing nurses and pharmacists did not have access to an electronic prescribing system. Across all professional groups, satisfaction with access to shared patient records to facilitate medicines access was low, with 38% (507/1327) of HCPs either not at all or only slightly satisfied. A number of barriers associated with CPs' role in supporting medicines access were identified and many HCPs lacked awareness of commissioned community pharmacy palliative medicines services. Respondents perceived that there would be a significant improvement in pain control if access to medicines was greater. Those HCPs with shared records access reported significantly lower pain estimates for their caseload patients.

Phase 3

In total, 40 patients and carers, 96 HCPs and seven commissioners were recruited and interviewed. Ninety-six patient record data extraction forms were completed and documents were analysed for 17 commissioned community pharmacy palliative medicines services.

Findings highlighted that the general practice model generated work for both patients and carers, and other HCPs, in their efforts to access prescriptions and have them dispensed, supplied and administered in a timely way. In comparison, patients on the caseload of a CNS prescriber experienced few delays and spent less effort accessing medicines, as these nurses undertook the work of co-ordinating access. These nurses' specialist knowledge of medicines and their ability to prescribe, as well as their familiarity with local networks of HCPs, was used to facilitate medicines access. Nevertheless, specialist nurses' lack of ability to use electronic prescribing systems limited the frequency with which they prescribed directly to

patients, generating more work for them in referring back to GPs for prescriptions, as well as work and delays for patients/carers who were required to either wait for a GP script or journey to a pharmacy with a handwritten nurse script. In the TSL case, the work and co-ordination required to access medicines was undertaken by HCPs and others staffing the support line. The TSL was a commissioned service, utilising access to shared electronic patient records and drawing on a wide network of local HCPs to mobilise swift access to medicines and information for patients. The focus on commissioned community pharmacy palliative care medicines services in case 3 highlighted that it can offer a swift, local access route to medicines, especially in times of urgent need. However, the service is insufficiently visible to HCPs and patients, and offers variable provision in terms of local geographical coverage, proximity to patients, hours open and the range and reliability of medicines in stock.

The work and co-ordination required to source prescriptions and medicines was apparent across all cases. In addition, much of this work was hidden, time-consuming and often frustrating or distressing. Relationships were a foundation for making this co-ordination activity successful. Co-ordination work was, in part, compensating for elements of the medicines access system that were poorly functioning (e.g. inaccessible GP services, lack of reliable pharmacy stock, and inadequate and inequitable access to electronic prescribing systems).

Costs for new prescriptions ranged from £60 to £91 and were more or less equivalent for repeat prescriptions. These cost differences were substantial when accounting for the eligible population over a 5-year period. Despite the small sample size, we did observe some statistically significant differences in costs between case sites. Reasonably robust findings were that case 1 (i.e. GP service) is associated with significantly higher hospital costs. The preliminary economic evaluation results indicated that the highest value service was the TSL service, which had an 85% chance of being the optimal choice. The TSL service and CNS prescriber services were both cheaper and more effective than the GP prescriber service. However, there was substantial uncertainty in the results.

Phase 4

Twenty-four interviews with CPs and eight interviews with wholesalers/distributors (WDs) were undertaken. Findings highlighted that, in general, the supply chain worked to ensure that there were stocks of palliative care medicines, but this was underpinned by immense levels of work by pharmacists to achieve this. Pharmacists navigated a challenging interface with WDs (via customer service centres), the Department of Health and Social Care (via the Drug Tariff) to ensure reimbursement and multiple systems [e.g. regulatory-, legal-, contractual-, organisational- and information technology (IT)-based systems]. In doing so, pharmacists were mindful of their duty to patients, which contributed to this onerous work, exacerbated by shortages. In contrast, WDs were focused upstream on their relationship with manufacturers and downstream across the piece with other pharmacies. Some of the WDs IT infrastructures and logistics were helpful to supply on the ground, resulting in same or next-day deliveries. However, other aspects of WDs focus upstream caused problems, for example via inadequate forecasting. WDs also had to be responsive to problems caused down the supply chain, for example by pharmacists bulk ordering. However, little resource went into maintaining relationships with pharmacists on the ground. A conceptual model of supply into community pharmacy was developed, illustrating the importance of relationship building and maintenance, meaningful information transfer, effective stock management and robust logistics infrastructure leads on the supply chain of palliative care medicines.

Phase 5

A workshop of 19 expert participants reviewed the study findings. Findings from the workshop included the following: participants endorsed study findings and generated implications (e.g. a need for greater interprofessional integration, communication and awareness); the need for improved access to shared records, particularly across the community, hospice and NHS interface, and for a multiprofessional prescriber workforce with universal access to electronic prescribing systems; and greater and swifter access to community pharmacy stock of palliative care medicines.

Conclusion

Accessing medicines required considerable co-ordination work. Delays in access were linked to service delivery models that were over-reliant on GP prescribing, community pharmacy medicines' unreliable stock and CNSs' lack of access to electronic prescribing. Key issues were relationships and team integration, diversifying the prescriber workforce, access to shared records and improved community pharmacy stock.

Implications

- Greater consideration should be given by service delivery commissioners and managers to implementing named EoL care co-ordinators.
- Resources are needed to support training for more palliative care nurse specialists to prescribe medicines independently to patients.
- Greater harmonisation of IT systems is needed so that all HCPs have access to shared electronic patient records across service organisation interfaces.
- All community-based prescribers, including nurses and pharmacists, require access to electronic prescribing systems, including in patients' homes.
- Commissioning telephone support services might offer single point-of-contact and cost-effective models of provision that can co-ordinate medicines access systems and act as information-giving hubs for EoL medicines and services.
- Greater integration of CPs within the wider primary and community health-care team is needed to ensure that they are embedded in the patient pathway and to facilitate information-sharing about patients and their medicines.
- Commissioning of community pharmacy services for palliative care would benefit from a shift to a more standardised core list of medicines, with a greater and more even distribution of pharmacies or other community hubs holding stock that are accessible OOH.
- Pharmaceutical WDs need to engage with CPs both individually and collectively for two-way communication about practices that reduce pharmacist work and best support palliative care medicines supply.
- Given the potential substantial cost differences between services, additional research, including a health economics evaluation, is required to generate further evidence to inform service provision decisions.

Study registration

This study is registered as CRD42017083563 and the trial is registered as ISRCTN12762104.

Funding

This project was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme and will be published in full in *Health and Social Care Delivery Research*; Vol. 10, No. 20. See the NIHR Journals Library website for further project information.

Health and Social Care Delivery Research

ISSN 2755-0060 (Print)

ISSN 2755-0079 (Online)

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb and NCBI Bookshelf.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hshr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the *Health and Social Care Delivery Research* journal

Reports are published in *Health and Social Care Delivery Research* (HSDR) if (1) they have resulted from work for the HSDR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HSDR programme

The HSDR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HSDR programme please visit the website at <https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm>

This report

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as project number 16/52/23. The contractual start date was in February 2018. The final report began editorial review in December 2020 and was accepted for publication in June 2021. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care.

Copyright © 2022 Latter *et al.* This work was produced by Latter *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaptation in any medium and for any purpose provided that it is properly attributed. See: <https://creativecommons.org/licenses/by/4.0/>. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

NIHR Journals Library Editor-in-Chief

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

NIHR Journals Library Editors

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Professor of Digital Health Care, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Andrée Le May Chair of NIHR Journals Library Editorial Group (HSDR, PGfAR, PHR journals) and Editor-in-Chief of HSDR, PGfAR, PHR journals

Professor Matthias Beck Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Consultant in Public Health, Delta Public Health Consulting Ltd, UK

Dr Peter Davidson Interim Chair of HTA and EME Editorial Board. Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Ms Tara Lamont Senior Adviser, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Catriona McDaid Reader in Trials, Department of Health Sciences, University of York, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Emeritus Professor of Wellbeing Research, University of Winchester, UK

Professor James Raftery Professor of Health Technology Assessment, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Rob Riemsma Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Professor Helen Roberts Professor of Child Health Research, Child and Adolescent Mental Health, Palliative Care and Paediatrics Unit, Population Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

Professor Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk