**Introduction**

Access to medicines is a vital part of palliative and end-of-life care. Without it symptoms cannot be effectively managed, causing high levels of distress. Patient access to medicines at home during the last 12 months of life is therefore critical for symptom control, and to prevent distress and unplanned admissions to hospital.

Anecdotal experiences from community practice suggested problems with different models of service delivery in relation to patient access to medicines in the last year of life and innovative methods of service delivery were unevaluated [1]. Therefore the response authors in collaboration with colleagues at the Universities of Bradford and Leeds, were successfully awarded funds to evaluate patient and carer access medicines at end-of-life within the context of models of service delivery. The NIHR funded ActMed Study (Accessing medicines at end-of-life: a multi-stakeholder, mixed method evaluation of service provision [https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/165223/#/](https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/165223/)) was conducted between February 2018 and November 2020, with the final report published in July 2022 [2].

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The authors are responding on behalf of the ActMed Study team.

**To what extent do people in England have access to good palliative care?**

The study found access to good palliative care was far from universal - patients and carers experienced difficulties and delays in being able to access medicines to control symptoms whilst being cared for at home.

The following factors were found to be limiting patient access to medicines as a key component of good palliative care:

1. **Coordinating access to medicines is time-consuming for patients, carers, and healthcare professionals alike and is burdensome.** Accessing medicines was found to be involve a complex set of activities from getting prescriptions (new and repeat), liaising with community pharmacy/practice dispensaries (and at times hospital pharmacies and private healthcare systems), through to arranging for collection/delivery. Patients accessed medicines and medical supplies from not just primary care, but secondary and private, paid-for care. This was played out against a clinical context of rapidly changing symptoms, creating an urgent need for supply of medicines into the home.

The study data found that for some patients and carers this complex process was confusing and burdensome, additionally there were high levels of coordination work undertaken by healthcare professionals. Some service delivery models were operating better than others to support timely access to medicines [3].

1. **Over-reliance on general practitioner prescribing and under-development of nurse prescribing is inefficient and causing delays in access.** In our survey of 1327 community based healthcare professionals less than a half (42%, 160/386) of specialist palliative care nurses and only a quarter (27%, 27/99) of generalist community nurses were trained to prescribe. Most common reasons for not training were: cost of training (31%, 155/508), lack of employer/colleague support (24%, 122/508), no backfill of their post available (18%, 92/508), no designated clinically-based trainer available (16%, 80/508) [4].
2. **Shared access to records between professional groups and across settings is inadequate and causing delays.** Access to shared records was a further key issue affecting medicines access. Clearly, being able to access patient records to check details of a patient’s medical and drug history are important in being able to prescribe or advise others to prescribe safely and quickly.

Data revealed a variable picture: those based in GP practices and community nurses had relatively high levels of access. For example 84% (421/499) of GPs could access GP out-of-hours records; 83% (82/99) of community nurses could access GP records; 73% (113/151) of primary care pharmacists (based in GP practices) could access GP out-of-hours records. However, palliative care specialist nurses in particular reported limited access to others’ records, whether paper or electronic: 44% (173/389) reported no access to GP records and 68% (264/389) were unable to access GP out-of-hours records.Health care staff also identified this as one of the top four solutions to problems with current service delivery (21%, 148/703) [4].

1. **Access to electronic prescribing systems by specialist palliative care nurse prescribers and community nurse prescribers is inadequate, delaying access.** Nurse specialist prescribers’ ability to facilitate medicines access was hampered by poor access to electronic prescribing systems. This meant they often deferred back to GPs to prescribe instead, and only prescribed directly to patients using a hand-written prescription pad script in certain situations such as when GPs were particularly difficult to access e.g. late in the day or at the end of the week [3]. Patients or carers were then required to travel to a pharmacy with a hand-written script.
2. **Pharmacists are not integrated into the wider primary and community-based healthcare team.** Many community pharmacists reported a lack of awareness of patients’ palliative status, which precluded their ability to help patients access medicines. Community pharmacists’ access to patient records was confined to the Summary Care Record. 11% of community pharmacists (25/219) “always” felt that lack of awareness of patients’ palliative status influenced their ability to help patients access medicines, 40% (87/219) answered “often” and 33% (71/219) answered “sometimes” [4].
3. **Community pharmacy stocks of palliative care medicines are unreliable**. Lack of reliable stock of the right medicines in community pharmacies was a key finding, even at pharmacies commissioned to provide stocks of palliative care medicines. This caused work for patients, carers and health professionals trying to source stock from other pharmacies, and delayed access and increased potential for distress [3].

Where commissioned services worked well, they were seen as providing a valuable service, however study findings also showed there were an insufficient number and uneven geographical spread of pharmacies in some areas, low awareness of services, variable medicines’ lists between and within services, and not all offered out-of-hours access [2, 4].

**How can palliative care be improved?**

We make the following policy recommendations to improve access to medicines, as part of good palliative care [5]:

1. **Implement named end-of-life care coordinators.** End-of life care co-ordinators should be implemented to act as single points of contact for patients and healthcare professionals, including initiating new or repeat prescriptions.
2. **Prioritise training for specialist palliative care nurses and community nurses to prescribe.** Health Education England should make resources available to hospices and community trusts for prescriber training, in particular given hospice-employed specialist nurses’ important contribution to patient care, and the potential benefits and cost-effectiveness of this service. Continued reliance on GP prescribing increases costs, work and time delays on an over-burdened service [6].
3. **Harmonise IT systems.** NHS Digital and local IT system suppliers need to collaborate to harmonise local IT systems so all health professionals have access to shared electronic patient records across GP, community and hospice interfaces, including remotely in patients’ homes. Continuing with current levels of lack of shared access risks delayed and unsafe prescribing.
4. **All prescribers require access to electronic prescribing systems, including in patients’ homes.** NHS Digital and local IT system suppliers need to work together to reduce current inequities in community-based professionals’ access to electronic prescribing systems. Continued, enforced reliance on hand-written scripts will deter some professionals from prescribing directly to patients and/or cause unnecessary journeys to pharmacies for patients and carers at a distressing time [6].
5. **Improve integration of community pharmacists into healthcare teams.** NHS England & Improvement as well as Integrated Care Systems and Primary Care Networks, need to drive integration of community pharmacists within the wider community and primary healthcare team and allow community pharmacist access to information about patients’ palliative care status, with patient consent, via an enhanced Summary Care Record or patient record access. Failure to do so will mean the potential for the community pharmacist workforce to contribute to good palliative care medicines access will remain unfulfilled [7].
6. **Commission standardised, equitably distributed stocks of medicines.** NHS England & Improvement and Integrated Care Systems should commission community pharmacy services for palliative care of rationalised, commonly-agreed core lists of medicines, with greater and more even distribution of pharmacies (or other community hubs holding stock which is also accessible out-of-hours), delivered swiftly and free-of-charge to patients’ homes.

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