Pharmacy teams are essential to driving responsive palliative care

Researchers from Marie Curie call for greater integration between pharmacy and palliative care teams to improve care quality, proposing a toolkit to bridge the gap between theory and practice.

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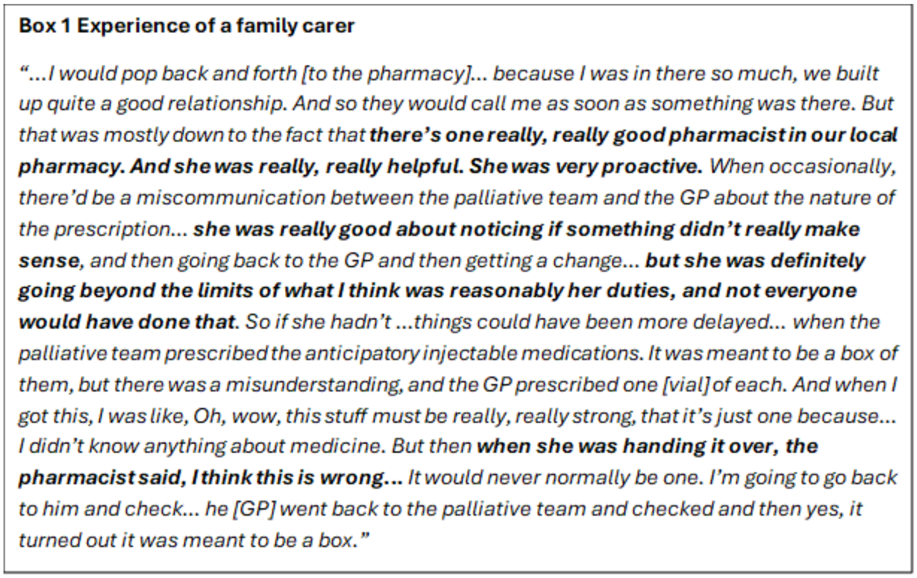
Palliative medicines management is an essential part of the complex activities required to deliver palliative care across organisations and locations, within and beyond the NHS in the UK. Good palliative care is only achieved when patients get maximum benefit and minimum harm from symptom control medication.

Medicines management in palliative care is complex because it requires multi-step processes to be enacted in the context of pre-existing social factors, such as medication safety within a multi-occupancy home; interactions between different needs, such as symbolic interpretations of medication use in the context of end-of-life care; and capacity for advocacy.[i,ii] Processes of decision-making, prescribing, monitoring and supply, administration, and stopping or disposing of medications are even more problematic when someone moves between their home, hospital and hospice settings, requiring the coordination of care across service boundaries.[iii]

It is perhaps, therefore, unsurprising that patients, carers and professionals experience numerous hassles in trying to get the right palliative medications at the right time. Approximately 20% of NHS serious incident reports involving patients receiving palliative care relate to prescription medications.[iv] Continuous subcutaneous infusions account for approximately 25% of palliative medication incidents.[v]

Palliative medicines management in the NHS

Poor medication management leads to unnecessary suffering for patients, their families, and carers. We need to develop systematic solutions to these problems that do not solely rely on individuals ‘going the extra mile’ as described by the family carer, quoted in Box 1.


Box 1 Experience of a family carer

"…I would pop back and forth [to the pharmacy]… because I was in there so much, we built up quite a good relationship. And so they would call me as soon as something was there. But that was mostly down to the fact that ***there's one really, really good pharmacist in our local pharmacy. And she was really, really helpful. She was very proactive.*** *When occasionally, there'd be a miscommunication between the palliative team and the GP about the nature of the prescription…* ***she was really good about noticing if something didn't really make sense****, and then going back to the GP and then getting a change…* ***but she was definitely going beyond the limits of what I think was reasonably her duties, and not everyone would have done that****. So if she hadn't …things could have been more delayed… when the palliative team prescribed the anticipatory injectable medications. It was meant to be a box of them, but there was a misunderstanding, and the GP prescribed one [vial] of each. And when I got this, I was like, Oh, wow, this stuff must be really, really strong, that it's just one because… I didn't know anything about medicine. But then* ***when she was handing it over, the pharmacist said, I think this is wrong…*** *It would never normally be one. I'm going to go back to him and check… he [GP] went back to the palliative team and checked and then yes, it turned out it was meant to be a box."*

Neither the human nor system costs of not getting palliative medication management right have been adequately explored. Hidden work that is unaccounted for in policies or service specifications is widespread and burdensome for patients, carers, and professionals.

While policies promote increasing palliative care in community settings, the system still lacks feasible ways to make this happen.[vi] Commissioning of pharmacy services and inclusion of pharmacists into palliative care are highly variable across the UK despite the 2023 NHS England specification for adult palliative and end-of-life care services including a requirement for input from pharmacists with specialist skills and experience in palliative care within multidisciplinary teams.[vii] Furthermore, integration of pharmacy services is a core tenet of WHO strategy to improve palliative care worldwide.[viii]

What needs to change?

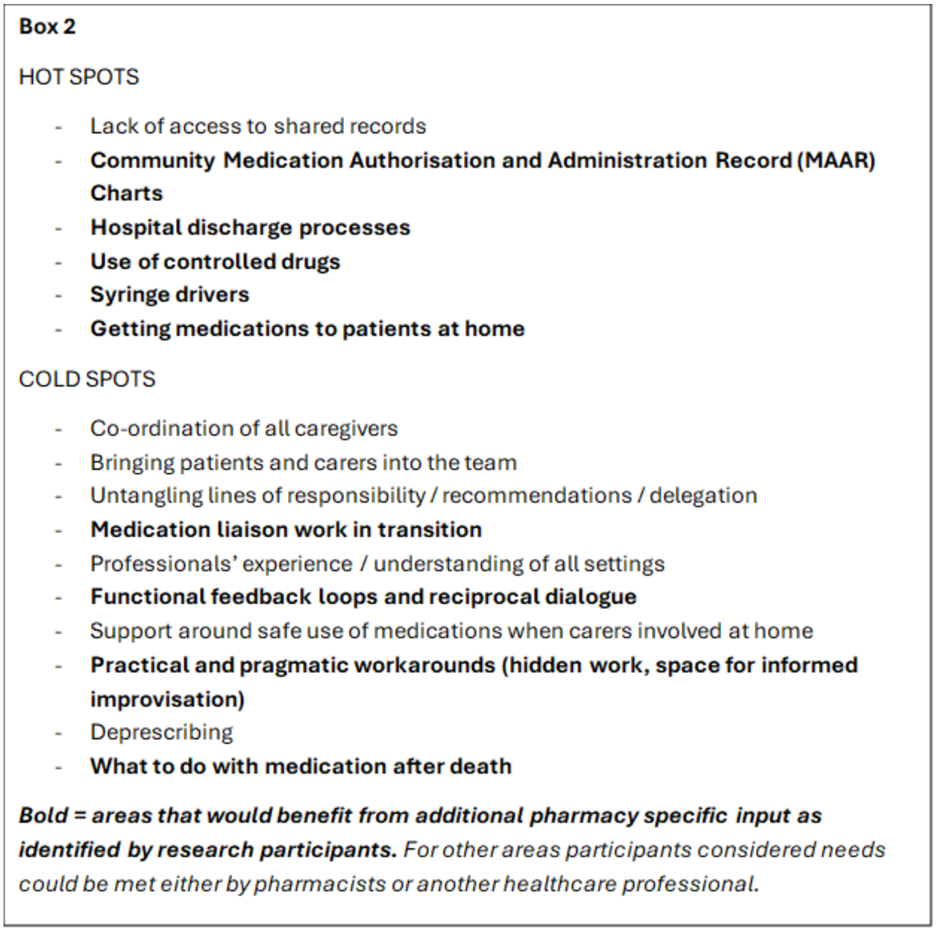
Ensuring access to 'the right medicines, at the right time, in the right place' for symptom control in palliative care requires a whole systems approach.

Commented [CW1]: In research? Or by policymakers?

Commented [SF2R1]: I think this makes our point clearer:

Neither the human nor system costs of not getting palliative medication management right have been adequately explored by policy-makers, system designers, funders or providers.

Commented [SF3]: We would like to replace 'feasible' with 'equitable and inclusive', please. [It is the fact that services are patchy is what we would like to convey].



Box 2

HOT SPOTS

- Lack of access to shared records
- **Community Medication Authorisation and Administration Record (MAAR) Charts**
- **Hospital discharge processes**
- **Use of controlled drugs**
- **Syringe drivers**
- **Getting medications to patients at home**

COLD SPOTS

- Co-ordination of all caregivers
- Bringing patients and carers into the team
- Untangling lines of responsibility / recommendations / delegation
- **Medication liaison work in transition**
- Professionals' experience / understanding of all settings
- **Functional feedback loops and reciprocal dialogue**
- Support around safe use of medications when carers involved at home
- **Practical and pragmatic workarounds (hidden work, space for informed improvisation)**
- Deprescribing
- **What to do with medication after death**

Bold = areas that would benefit from additional pharmacy specific input as identified by research participants. *For other areas participants considered needs could be met either by pharmacists or another healthcare professional.*

Source: Getting prescription medications right at home, in hospital & hospice

We conducted a theoretically informed empirical ethnography ‘Getting prescription medications right at home, in hospital & hospice’ using Activity Theory – a ‘whole system’ method to understand experiences of everyone involved in managing palliative medications.[ix] This identified ‘hot’ (widely recognised challenges) and ‘cold’ (issues requiring greater attention) spots in the current system that need to be addressed to improve safety and confidence (see Box 2).

Participants identified the inclusion of pharmacists, and other pharmacy professionals, in palliative care services as essential for improving medication management processes. All palliative care patients receiving medication for symptom control should have direct and regular access to a pharmacist, trained in palliative care. All patients should also be able to receive a structured medication review and have shared decision-making conversations about deprescribing. This can only be achieved if the NHS increases the use of palliative care pharmacists in community services, acute hospital teams and hospices to enable working across system boundaries.[x]

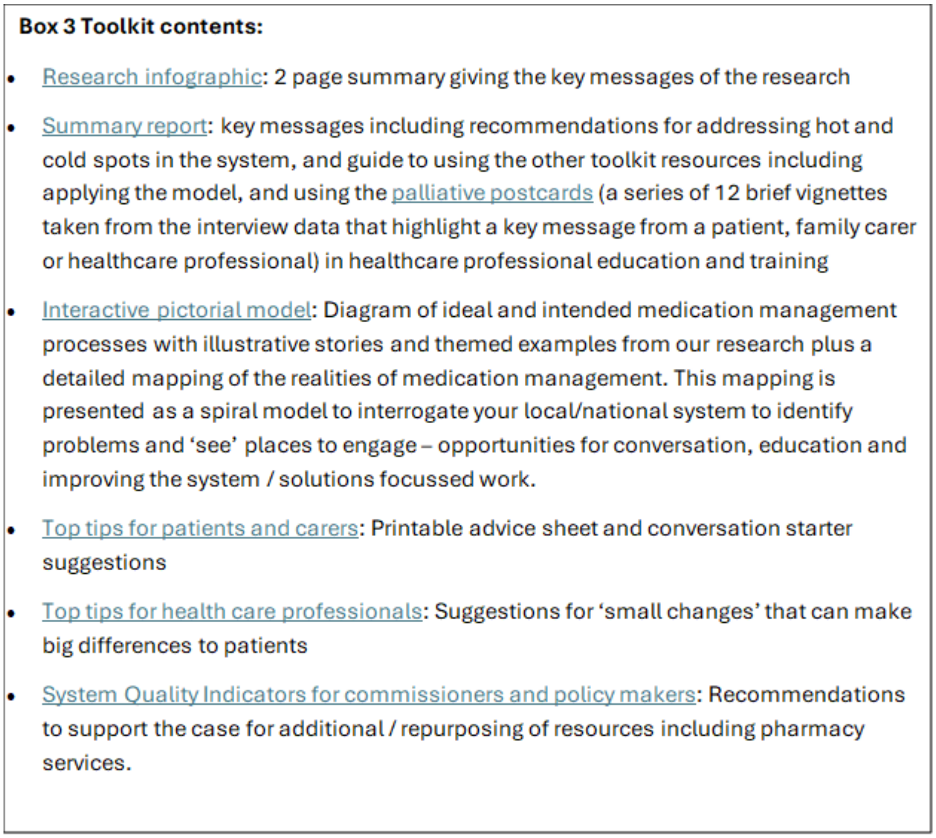
Our evidence-based toolkit

Healthcare professionals will always need to work around system flaws to provide personalised palliative care, even as we advocate for wider structural changes in how palliative medicines are managed.

Meaningful choice, including prioritising ‘what matters most’ for someone receiving palliative care can rarely, if ever, be achieved without engaging in positive risk-taking. Therefore, building trust between patients, carers, and healthcare professionals, and reducing the sense of isolation is an essential component to improving palliative medicines management.

To assist in this, we created an evidence-based toolkit (see Box 3) to help bridge the gap between research and practice. The toolkit aims to support personalised improvements in palliative medication management systems in different contexts. Evidence to support the toolkit comes from observing more than 120 hours of everyday practice and informal conversations at home, in hospital and in hospice. We spoke to 83 patients, informal carers, and professionals, mapping out who does what and when.

The toolkit can be used as a self-assessment to highlight potential ways of improving the planning, funding and provision of services. We have also found it effective in prompting communication between stakeholders across system boundaries, helping to develop shared solutions, learning from each other.[xi]



Box 3 Toolkit contents:

- Research infographic: 2 page summary giving the key messages of the research
- Summary report: key messages including recommendations for addressing hot and cold spots in the system, and guide to using the other toolkit resources including applying the model, and using the palliative postcards (a series of 12 brief vignettes taken from the interview data that highlight a key message from a patient, family carer or healthcare professional) in healthcare professional education and training
- Interactive pictorial model: Diagram of ideal and intended medication management processes with illustrative stories and themed examples from our research plus a detailed mapping of the realities of medication management. This mapping is presented as a spiral model to interrogate your local/national system to identify problems and 'see' places to engage – opportunities for conversation, education and improving the system / solutions focussed work.
- Top tips for patients and carers: Printable advice sheet and conversation starter suggestions
- Top tips for health care professionals: Suggestions for 'small changes' that can make big differences to patients
- System Quality Indicators for commissioners and policy makers: Recommendations to support the case for additional / repurposing of resources including pharmacy services.

Adequate resourcing

We need better systems that help people collaborate effectively. Finding ways to facilitate a two-way discussion across roles, teams, organisations and locations should be prioritised. Building strong working relationships with colleagues in this way can help reduce workload and make the wider healthcare system more effective. Patients and carers need to be supported to talk about how they take their medications without fear of judgement, and they need to understand who the different professionals are that can help them.

Commented [SF4]: I think the key point we wish to make here is that synchronous discussion at the time of decisions being made should take priority over asynchronous communication / messages being left for someone to pick up.

Commented [SF5R4]: Please can we keep 'in real time'

Commented [SF6]: We were also trying to make the point that they need to identify who to communicate with both within settings and across care settings, i.e. hospital / hospice / community

Commented [SF7R6]: Please can we keep in 'across different care settings'

Community pharmacy teams (and pharmacists in hospitals or hospices working with people receiving palliative care) must be adequately resourced and trained to support medication reviews with patients and carers, tailoring advice to individual needs, explaining reasons for changes in medications, and advising on practicalities of self-administration.

The burden placed on carers would also be reduced through services that deliver medication to homes, and accept medications that are no longer required (including after a patient dies) – even if they were dispensed from another pharmacy. Greater use of specialist link workers, such as integrated care community pharmacy technicians, could facilitate better communication between different parts of the healthcare system.

A healthcare system that learns from experience, is one that seeks to improve. However, evidence and learning need to be translated into practical pragmatic tools for practice. A toolkit such as ours offers a way for everyone invested in improving palliative medicines management to work together to reduce waste and increase effective use of resources, in addition to improving the quality of care.

To make this change sustainable pharmacists and pharmacy services must be integrated into palliative care models regardless of whether the patient is at home, in hospital or hospice.

Commented [SF8]: You may want to add about the RPS Policy refresh that is being undertaken for Palliative and End of Life Care that is due to be published in 2025.

Find out more:

The official launch of our Toolkit will take place online at the Marie Curie Virtual Conference, Thursday 13th February 2025 and the session recording available afterwards. To register: https://mariecurie.ivent-pro.com/events/research-conference-2025/login

Further information about applying the toolkit can be found in *What we learned from the REACT palliative care service* Cross reference Bradford blog submitted by Zoe Edwards

Additional resources for community pharmacies are available from the RPS/Marie Curie Daffodil Standards initiative: https://www.rpharms.com/recognition/setting-professional-standards/daffodil-standards

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of Oulu, Finland) & Karen Mattick (University of Exeter Medical School, University of Exeter, UK)

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[Currently linked as footnotes].

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