Challenges facing cancer care and guidance on prioritising its safe delivery: lessons from the COVID-19 pandemic

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Abstract

The COVID-19 pandemic challenged the NHS to make rapid adjustments to practice to ensure that patients could continue to access vital treatments while reducing the risk of infection. A roundtable discussion was convened, including professionals from cancer care delivery and those working in patient involvement, to discuss experiences during the pandemic and to offer recommendations for the safe transition and implementation of cancer care in the community setting.

Key words: Cancer care; Chemotherapy; Integrated care systems; Patient perspective; Vascular access

Introduction

The COVID-19 pandemic forced changes to service delivery across healthcare. While some of these were by necessity temporary, others offered opportunities to change the way that healthcare is delivered for the benefit of both patients and healthcare professionals. In September 2021, a group of key stakeholders with experience in running integrated care systems to deliver cancer care and patient and public involvement came together to discuss their experiences during the pandemic and to offer recommendations for the safe transition and implementation of cancer care in the community setting. The meeting was sponsored by Becton Dickinson (BD).

Integrated care systems

Integrated care systems grew out of sustainability and transformation partnerships, local partnerships formed in 2016 to develop long-term plans for the future of health and care services in their area. Integrated care systems are the latest large-scale initiative to be introduced into the NHS and they are charged with taking a population health perspective rather than an organisational perspective. Following Royal Assent of the Health and Care Act 2022, 42 integrated care systems have been established across England on a statutory basis on 1 July 2022, empowering them to better join up health and care services, improve population health and reduce health inequalities.

The current proposals mean that each integrated care system would be led by an NHS integrated care board, an organisation with responsibility for NHS functions and budgets, and an integrated care partnership, a statutory committee bringing together all system partners to produce a health and care strategy.

Integrated care systems are partnerships that bring together providers and commissioners of NHS services across a geographical area with local authorities and other local partners. Looking at it this way, a treatment pathway might cut across organisational boundaries, with individual health professionals or services just components of the overall system. To be truly successful, integrated care systems require community engagement through outreach services and the financial system underpinning the integrated service will likely need also to be re-engineered towards the kind of population it serves.

Before the start of the COVID-19 pandemic, some trusts were already using integrated care systems as a framework for delivering cancer care in the community setting. The challenges associated with safe delivery of ongoing treatment to clinically extremely vulnerable patients while limiting their exposure to the coronavirus increased both the urgency to expand pilot schemes and interest from other trusts.

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Optimising patient care pathways

Patient care pathways should aim to deliver clinical, financial and operational improvements across the system. For commissioners and clinicians looking to move isolated parts of a patient care pathway out of an acute environment into the community, the process needs to start with a review of the whole care pathway.

Key to this process is mapping the whole care pathway across the integrated care system. Everyone, including staff and patient partners (patients, carers, members of patient support groups and members of key committees), involved in the pathway must be included in the discussion to identify potential bottlenecks or waiting lists; inefficiencies and/or duplications; non-adherence to current practice and/or regulations; observed incidents and errors; and any inherent risks. Patient partners must be involved at all stages. The success of the scheme will also rely on having enough staff with the right skills mix, ensuring that roles identified as critical are covered during sick leave or holiday periods, and identifying any training needs to ensure this is deliverable. Facilities and supply chains must also be available or adaptable. Improvements in service optimisation should create financial savings and bring wider benefits for the organisation and/or patients.

Only very rarely is a move into community care the first of its kind – there will be reports of other people's experience (including model examples, reviews of strengths and weaknesses and cost–benefit analyses) that can be used to inform and support proposed changes. It is essential to ensure that any changes are safe and in line with best practice set out in national and/or local guidelines. Commissioning teams must be part of this review because key performance indicators are often linked to the evidence underpinning service redesign and, of course, to adherence to regulations.

It is essential to establish a demand for such a change – do patients need it, is there a budgetary need for change, are operational changes mandated? For the move to be successful, changes should be realistic, efficient, financially viable and focused on the patient. The move should not increase risks in other parts of the system (eg by redeploying human or budgetary resources, creating shortages elsewhere).

Implementation of service changes in response to the COVID-19 pandemic

Many treatments for cancer are associated with a degree of immunosuppression, increasing patients' vulnerability to all forms of infection. Cancer treatment centres therefore need to reduce patients' potential for exposure to the virus, which in many cases meant that in-clinic appointments were cancelled, at least temporarily. The trusts represented in this discussion were able to respond quickly to the COVID-19 pandemic to ensure that patients were able to access cancer care.

At the Christie Hospital in Manchester, some of the nurse-led clinics for systemic anti-cancer therapy in hospital were paused until alternative locations for these clinics could be found. These nurse-led clinics operated alongside the existing Christie at Home service (established in 2016 to allow patients to receive chemotherapy and immunotherapy treatments in their own homes; The Christie NHS Foundation Trust, 2021) in local hospices, another hospital, medical centres and the mobile chemotherapy unit required to continue to offer care closer to home in some geographical areas. The changes were made very quickly, so that patients' access to care did not change. Similarly, oncologist appointments were conducted over the phone, with a few piloting video conferencing, and this is likely to continue for patients who want it – for example those who have to make a long trip to the hospital for a 10-minute appointment in which the oncologist only needs to confirm that the patient can go forward for treatment. As long as patients have access to video conferencing, technology means that scans and other results can still be shared with the patient in a virtual clinic and patients can still see the face of the person they are speaking to. During COVID-19, when visitors were not able to accompany patients to the hospital, virtual clinics also allowed family members and carers to sit alongside the patient during the consultation.

The Christie's pharmacy homecare team introduced electronic records for tracking medicines from the request to delivery to the patient (including mode of delivery). This improved governance, saved time taking telephone calls and made troubleshooting easier when patients called with queries. This system is still in place. Initially, staff (mainly from non-clinical roles) from other areas of the hospital were redeployed to delivering oral cancer medicines, which was much appreciated by patients, but this delivery process stopped when the staff were able to return to their usual roles.

From the hospital's perspective, the workload significantly increased over the COVID-19 period and the number of treatments delivered has exceeded 2019–20 activity, thanks to the changes that have been introduced. From the patient's perspective, care continued as normal. Patients reported that they felt safe because they did not have to come to the hospital (eliminating the need to rely on relatives in the absence of public transport options at the height of the pandemic) and then sit in a waiting area in a main acute hospital. Patients also came to appreciate the convenience of treatment closer to, or at home. Going forward, patients will have more choice about how and where they receive cancer care from the Christie as closer to home services expand.

At the Royal Marsden Trust, being a cancer hub throughout the pandemic, services were offered to more people or to different people beyond the hospital's traditional clients, resulting in a greatly increased number of patients. An important change was the introduction of technology to aid service delivery. The move to telephone and virtual consultations and meetings whenever possible was an important element in this, and one which is likely to stay. The Trust will be introducing a new patient portal to further upgrade its virtual interactions with patients, without losing sight of the fact that not all patients have online access.

The Royal Berkshire Hospital had plans to increase patient choice in the setting for their cancer care before the pandemic and the onset of lockdown accelerated this process. The use of technology was, and is, key to delivery of cancer care in the community, but it is not a panacea. Any changes need to keep patients and their safety at their centre. Audits of other trusts have indicated that while virtual appointments were tolerated during the pandemic, many patients prefer to have face-to-face appointments. Going forward, it is likely that virtual appointments will coexist with face-to-face appointments for patients who want them. This will require treatment centres to balance what they want to keep and what they want to review based on their needs, patient safety issues and patient preferences.

Identifying and overcoming challenges in planning and implementing optimal vascular access, focusing on patient safety

The real challenge for planning and implementing optimal vascular access for community cancer care lie in the availability of a sufficient and appropriately trained workforce.

It is generally accepted that cancer therapies should not be administered by community nurses who have not received specialist training. If nurses are to deliver systemic anti-cancer therapy in the community the nurses doing it need to be 'chemotherapy (or systemic anti-cancer therapy) competent', having completed training and been assessed as competent. In general terms nearly all specialist chemotherapy units (and hence the trained nurses) are based at, or in services run from, an acute trust, with the exception of some third party providers (such as Healthcare at Home) who deliver chemotherapy at home privately. Dialysis would be a good model for some hospitals that have tried to move chemotherapy or systemic anti-cancer therapy closer to home via smaller chemotherapy units away from big sites, although these are still generally run by acute trusts.

In the secondary care setting chemotherapy is delivered via a peripheral cannula or central venous catheters (ports or peripherally inserted central catheters). The latter may be preferred for home-based systemic anti-cancer therapy administration because they are safer and present a lower risk of infection; however, these devices have to be inserted by an expert based in the hospital, meaning that the patient currently has to go to there for this procedure.

In addition to staffing issues, the system may also cause challenges to the community delivery of systemic anti-cancer therapy. Regular blood tests provide information on the patient's general health and may alert the team to the need to reduce the dose or even delay chemotherapy. It is essential that the team has timely access to these results and the phlebotomy service needs clear guidance on where and to whom the results should be reported to avoid delays.

Of note, the Royal Marsden Trust no longer offers community services as a result of resource allocation and optimal organisation.

The Christie at Home service benefits from several important advantages. The hospital itself is a specialist centre for oncology which provides training and support to peripheral sites and has established nurse-led protocols for the treatments, including clear inclusion and exclusion criteria, to ensure safe delivery. It manages its own workforce of specialists and support staff and has service level agreements with outsourcing companies for some services.

An alternative to providing cancer care at home, with the inherent challenges described above, is to provide cancer care closer to home – for example using a hub and spoke model with a large specialist centre at the middle linked to multiple chemotherapy units in smaller hospitals, with appropriately trained staff, so that patients do not have to travel so far for their appointments.

How can automation play a role in the safe delivery of cancer care?

For the purposes of this meeting, medical automation was defined as: ‘the controlled operation of a diagnostic or therapeutic process or system by mechanical or electronic means that augments human capabilities for observation, effort, and decision’. In terms of integrated care systems, ubiquitous access to electronic care records, pharmacy records and imaging could certainly facilitate local delivery of systemic anti-cancer therapy by acute oncology teams travelling to peripheral hospitals and clinics (and possibly at home), but the NHS is not yet in a position to implement this.

Currently, the rate at which digital innovations are being delivered is challenging the ability to obtain evidence that proves that they deliver good, safe care, which is essential before they can be systematically rolled out and adopted. Trials that demonstrate the safety of technologies rather than interventions are harder to design and implement than trials of new medicines and devices.

Some innovations adopted in the NHS were not new per se, but new to the NHS. Examples are automated call answering and the use of apps for monitoring symptoms and side effects and to allow patients to communicate with clinical staff. Although introduced or expanded during the pandemic, these technologies are likely to remain in the NHS because they have the potential to free up clinical time or increase convenience for patients. For example, automated call answering has the potential to collect routine reports from patients undergoing systemic anti-cancer therapy using the same series of questions that systemic anti-cancer therapy nurses work through in their regular follow-ups with patients. Clearly, such a system would need to recognise red flags that indicate that human intervention was necessary, but it would reduce the number of calls and appointments that systemic anti-cancer therapy nurses need to make each day.

The vast amounts of record keeping required by the NHS is another area that could benefit from automation. In Manchester, electronic cancer care records containing information not available in their GP record, such as the patient’s notes, laboratory results, drugs dispensed, can be shared within the Trust and with hospitals outside the Trust if the patient is admitted elsewhere. In cancer care, it is possible that data from the electronic prescribing system (including information about procurement, prescription fulfilment and even data from smart pumps used to administer medication) could, in the future, also be added to the record. If such a system works well, it would play an important role in keeping patients safe and cutting down the burden of paperwork for systemic anti-cancer therapy nurses, ultimately allowing more patients to be treated. However, the system is not yet ready to roll out.

As mentioned previously, the Royal Marsden Trust is developing new electronic patient portals that are similarly designed to give patients and Trust staff easy access to patient records.

Projects like this and the development of patient apps require a lot of data to be collected and analysed during the development phase to allow the technology to be refined to increase its accuracy and safety. Ironically, the development of technology that will save time requires a lot of resource during the development phase and makes projects like this hard to prioritise when the workload is high.

The development of artificial intelligence and machine learning-based applications for the detection of cancer is being trialled and may be in routine use in a matter of years. A stumbling block has been to integrate this technology into the clinical workflow in a way that is supportive and helpful to clinicians. Work is ongoing to overcome this: artificial intelligence is routinely being incorporated in clinical trials and it seems likely that this will trickle down into day-to-day practice. Indeed, the Royal College of Radiologists is already providing information on artificial intelligence for people working in clinical oncology and clinical radiology.

A last point also relates to the quantity of data that automated systems can accumulate. Analysing these data could allow targeting of messages about the need for members of the public to present for screening; refinement of resources to address particular local issues in cancer care; and (with additional use of machine learning) improved decision making regarding cancer care.

How can industry help to deliver safe cancer care?

Sponsorship of multidisciplinary meetings at which skills, experience and best practice can be shared would help to support the roll-out of the service changes described above. NHS staff are renowned for their willingness to share standard operating procedures and processes. Networking opportunities, visits to projects and access to the people running the care pathway are very helpful to provide a clear understanding of the challenges and benefits. Sponsoring the production of literature based on, or to support, such meetings would also be welcome.

More controversially, funding studies designed to mine some of the data held in the NHS could provide information to support practice changes. While there are some concerns about the ownership and sharing of health data, the aims and objectives of an industry-sponsored data mining project – and the specific role of the sponsor – would need to be very clearly and carefully communicated to patients and staff.

How can the NHS demand more from industry?

Practitioners sometimes feel that they do not have ready access to the data and evidence for the drugs and equipment they use in order to support their decision making.

An example of why this is important was provided by the Christie at Home service. Immunotherapy for home delivery is supplied in closed systems rather than ready compounded. This means that if, after assessing the patient, the nurse decides not to administer the therapy it can be returned to the pharmacy rather than wasted. Although this is clearly a good idea, there is a paucity of data and evidence concerning the safety of these devices. Data supplied by manufacturers of closed system transfer devices tend to focus on microbial ingress as opposed to potential operator contamination with systemic anti-cancer therapy drugs.

Another example concerns the need for answers to questions about ‘older’ drugs which are no longer the subject of ongoing research and for which pharmacists are just referred to the drug label. These include questions around groups of patients in whom a drug will give optimal results (including low rates of side effects) and, conversely, those for whom a particular drug will no longer be effective or is likely to be hard to tolerate. A more flexible response to answering these questions would help pharmacists to ensure that therapy is likely to be safe for specific patients.

Just as the NHS is striving to include the patient voice in its planning and decision making, it would be good to see pharmaceutical and device companies making more efforts to involve patients in trial management groups. This is increasingly the case for studies and initiatives instigated by the Trusts represented at this meeting.

Examples of the value that patients, carers and members of the public can add to trial management committees include the content and layout of the information provided to trial participants and insight on potential endpoints. In the latter case, the trial sponsor and investigators tend to assume that survival is the most important endpoint for a study in patients with cancer. Patients do not always agree and may prioritise quality of life, for example, over duration of survival. There is a wealth of knowledge within the NHS on finding and involving diverse patients and carers in clinical trial committees that can be made available to pharmaceutical and device companies.

Obtaining funding for initiatives in cancer care

Funding for new projects and initiatives can come from external sources (ie new money) or from creating efficiencies in existing care pathways that release funding for other purposes. Creating efficiencies in existing care pathways starts with a deep review of current practice. Ordinarily, this might take 6–12 months, but during the pandemic this timescale was able to be reduced to weeks.

New money might take the form of transformation money and might come from people and organisations who might not immediately benefit from the project. Organisations known to respond to this type of request include Health Education England and third sector organisations such as Macmillan, Hospice UK and the various cancer alliances. These organisations seem keen to support clinical projects, such as the delivery of systemic anti-cancer therapy in hospices, that provide benefits to people living with and beyond cancer – not just patients, but their families and loved ones who are going on the cancer journey with them.

Identifying the benefit to patients is critical to presenting a successful bid for funding. The best way to ensure that the patient benefit is at the heart of the project is to involve patients from the very beginning and across all the phases of the project, including the team that pitches for funding. The patient voice is very powerful and must not be ignored (Box 1). It is important to include representatives of all key groups involved in running the service. For cancer care, inclusion of pharmacy representatives alongside the clinical

Box 1. The patient's view

Of the areas discussed, from a patient perspective, it is really encouraging to see the emphasis being placed on, where possible, offering patient choice. From discussions I have had with other cancer patients, it is clear that their personal circumstances, stage of life, disease and so on all lead to different preferences with regard to some of the cancer care options being discussed.

For example, I would personally value consultations being held virtually for all the reasons discussed – being able to have other people attend with me, see scans (I'm not normally offered this option), no travel time. However, I ran a poll on my Instagram stories where I am connected with hundreds of cancer patients and there was a strong preference for in-person consultations.

Equally, there is a split view on chemotherapy or immunotherapy being delivered in patients' homes. I would personally feel more comfortable in hospital or a chemotherapy clinic as I have very small veins and there is the potential risk of chemotherapy leaking from my veins. If this happens, it often takes one or more chemotherapy nurses or healthcare practitioners to successfully insert the catheter. Access to this gathering of resources is more important to me, and I also prefer to separate my chemotherapy treatment and my home. However, responses from Instagram showed a strong preference for the option to have chemotherapy delivered at home.

In addition, not all areas have community nurses who have been trained on how to flush a PICC (peripherally inserted central catheter) line, so for these patients, having to go in every week to have their PICC line flushed during a gruelling course of chemotherapy is not ideal. The general consensus was that having chemotherapy units connected to hospitals was a good compromise as this allows access to trained resource and treatment of multiple patients but with a shorter travel time for patients.

Being able to access our patient records electronically would be a great advantage. I commend the approach to build in the concept of the patient voice when exploring the potential to change cancer treatment.

As patients, we appreciate all those involved in facilitating cancer care as it exists today. Any further changes or options for flexibility would be welcomed, particularly if patients are able to be given choice, within the financial and resource constraints of the NHS.

Jennifer de Chickera, breast cancer (2021) and Hodgkin lymphoma (2011) patient staff and commissioners is highly recommended to identify any holes in the plan that could prove disastrous later in the process.

Table 1 outlines some practical recommendations offered by the panel based on their experiences.

Conclusions

The COVID-19 pandemic highlighted the benefits of working with patients as partners, giving them greater voice and choice in how their care is delivered.

The pandemic challenged the NHS to make rapid adjustments to its practices to ensure that patients with serious illnesses such as cancer could continue to access treatment without exposing them to unnecessary risk. Technology was widely used to facilitate consultations and the prescribing and delivery of medicines to reduce or even eliminate the need for patients to attend hospitals. Automation became further embedded in the NHS and demonstrated its potential to increase patient safety, release time spent on manual tasks to allow more patients to be seen and increase convenience for staff and patients. It is likely that many of these changes will become permanent – either as a replacement for, or to augment, existing clinical practice, although in some areas, particularly pharmacy, there are challenges around monitoring of medicines and governance issues that still need to be addressed.

During the pandemic expert staff from the secondary care setting were made available to work in the primary care or community setting. To continue to deliver systemic anti-cancer therapy outside oncology wards, either in patients' homes or in hub and spoke models of care, there needs to be greater integration of the specialist secondary care workforce with community resources. There is a model for this kind of system in the way that dialysis is delivered outside the secondary care setting. Some innovative thinking will be needed – such as exhibited in the Christie at Home service – to deliver this for patients with cancer.

In the longer term, one measure of how successful the changes have been will be the numbers of patients presenting for cancer screening and diagnosis. Many patients who found signs and symptoms of cancer during the pandemic were scared to attend for investigation, and there were also delays in referrals and diagnoses.

Money is always a stumbling block when planning any service level change in the NHS: one positive aspect of the pandemic for Trusts represented at this meeting was the ready availability of funding for the changes they needed to make. It is unlikely that this situation will persist in the future but, having identified opportunities for radical changes that benefit both the system and patients, it would be encouraging if implementation was not unduly

Table 1. Practical recommendations for colleagues planning to introduce integrated care systems to deliver cancer care outside the secondary care setting
Involve all interested parties in process mapping and design of integrated care systems: make sure that patient partners are involved at as many levels as possible to ensure their voice is heard
Establish reliable lines of communication with colleagues throughout the Trust, with colleagues in other trusts and with external providers
Build resilience into the system. Ensure staffing levels reflect current and future needs across the system. This should include opportunities for training and education to ensure that staff can move up and new staff are being prepared to come into the system
Look for opportunities to innovate: investigate alternative, safer ways to deliver medicines outside the secondary care setting; investigate the safe use of technology to engage patients while reducing workload
Do not reinvent the wheel – look for opportunities to share best practice; investigate what other people are doing and learn from them
Funding is probably going to be more easily obtained by reviewing care pathways than by obtaining new money, but do not hesitate to approach potential partners with schemes that can deliver clear benefits for patients and the community in general
Be open to a change in mindset: without that, all the other elements will not be sufficient to deliver the desired changes

Key points

- The pandemic challenged the NHS to make rapid adjustments to its practices to ensure that patients with serious illnesses such as cancer could continue to access treatment without exposing them to unnecessary risk.
- Use of technology and automation were critical to these adjustments.
- To continue to deliver systemic anti-cancer therapy outside oncology wards, there needs to be greater integration of the specialist secondary care workforce with community resources.
- Funding is likely to be more easily obtained by reviewing care pathways than by obtaining new money.
- Patient and public representation in the design of integrated care systems will help to ensure that they provide wider community benefits to help achieve their aims.

held back by prolonged arguments over funding. Patient and public representation in the design stages of an integrated care system will help to ensure that it is built around the provision of wider community benefits that will help it to achieve its aim.

A slightly frustrating observation is that it took a pandemic to prove that the NHS can be both a reactive and proactive organisation and bring in service redesigns quickly when necessary. One explanation for this is that everybody had a single goal – this is an important lesson to carry forward for future service redesigns. Of course, it helped that the NHS was given the money and personnel that it needed to make these changes happen and they were used quickly and sensibly and helped to achieve some longstanding desires for change.

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