Health Services Safety Investigations Body

Investigation report

Workforce and patient safety: primary and community care co-ordination for people with long-term conditions

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Patient safety themes, NHS staff

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A note of acknowledgement

We would like to thank all the patients, families and carers who gave their time to speak to us. Some of their experiences are documented in this report, but similar experiences were described to us by many other people. We would also like to thank the healthcare staff who engaged with the investigation for their openness and willingness to support improvements in this area of care.

About this report

In June 2023 a series of investigations on the theme of 'workforce and patient safety' was launched by HSSIB's predecessor organisation, the Healthcare Safety Investigation Branch. There are five investigations in the series which consider how working conditions in the NHS can be optimised to support patient safety, while maintaining and improving staff wellbeing. All investigations under the 'workforce and patient safety' theme have been completed under the NHS England (Healthcare Safety Investigation Branch) Directions 2022.

This report describes the findings of the fourth of these investigations. Other reports in the series that have been published to date are:

- Workforce and patient safety: temporary staff – involvement in patient safety investigations (published March 2024)
- Workforce and patient safety: digital tools for online consultation in general practice (published July 2024)
- Workforce and patient safety: temporary staff - integration into healthcare providers (published September 2024).

This report is intended for healthcare organisations, policymakers and the public to help improve patient safety in relation to co-ordinating care for people with long-term or complex healthcare needs. For readers less familiar with this area of healthcare, key terms are defined in the background detail is explained in section 1 and glossary on section 6.

Executive summary

Background

This investigation focuses on people with long-term conditions and how their care is co-ordinated. The investigation considers the role of ‘care co-ordinator’ to understand how care is co-ordinated for people with long-term conditions within the existing workforce.

People who have a long-term condition may be in contact with multiple health and care organisations and may experience harm if their care is not co-ordinated. They may also be admitted and discharged from hospital on a regular basis. Sometimes people with long-term conditions can manage contact and information flow to and from the different organisations they are seeing. Sometimes a family member or friend acts as that person who contacts and co-ordinates health and care services to ensure the person they are caring for gets the care they need. However, it can be difficult for patients and carers to navigate their way through a complex health and care system, particularly if they have multiple long-term conditions.

The investigation

The investigation spoke to patients and carers in focus groups and on a one-to-one basis; some of their experiences are described in vignettes in the report. It engaged with healthcare providers, integrated care boards, national bodies, and charities and the voluntary sector to understand the challenges around providing care co-ordination across multiple providers.

Findings

- The NHS has produced a definition of the professional role of NHS care co-ordinator. However, there is variation in how this role is implemented.
- Other national organisations have different definitions of care co-ordination and care navigation, which can create ambiguity for people overseeing these roles.
- There is not a single person/role/organisation responsible for co-ordinating care for people with long-term or complex health and care needs across multiple health and care organisations.
- The health and care system frequently fails to support care co-ordination across multiple care pathways and instead focuses on individual diseases or issues. This can leave people who have complex long-term conditions with uncoordinated care.
- Accessing and navigating health and care services can be difficult and complex, and patients and carers would like improved service integration and care co-ordination.
- Patients and carers act as a central point for information and contact for providers, but when they are unwell or unable to do this, care can be impacted.
- People who are unable to navigate the health and care system can experience deterioration of health, miss appointments or their care may become delayed or forgotten about, meaning they may need more intense treatment in the future or longer stays in hospital.
- Patients and carers have to retell their health history to different health and care providers. They believe the system is not joined up and that information does not flow across health and care organisations, or that different parts of the system cannot access information from other providers.
- When patients are discharged from a health or care setting out of normal working hours they do not always know who they can speak to about any concerns or their ongoing care.
- Different methods of sharing health and care information can create an information gap, particularly out of hours and at the weekend, resulting in a situation where not all health and care staff have the appropriate information to make decisions.
- Patients and carers can feel exhausted, burnt out, frustrated, angry and guilty, among other emotions. Patients and carers physical and mental health may deteriorate because of the extra burden of navigating the health and care system.
- Patients and carers may disengage with the health and care system because they are exhausted and frustrated. This may lead to poor outcomes for both patients and carers.
- There are different ways of supporting care co-ordination across the system, some of which are assisted by the charity sector.

HSSIB makes the following safety recommendations

Safety recommendation R/2025/059:

HSSIB recommends that NHS England/Department of Health and Social Care, working with other relevant organisations, reviews and evaluates the implementation of the care co-ordinator role. This is to ensure that all patients with long-term conditions have their care co-ordinated and that they have a single point of contact 24 hours a day, 7 days a week, to help them with any queries or concerns that they may have.

Safety recommendation R/2025/060:

HSSIB recommends that the Department of Health and Social Care works with NHS England and other stakeholders, to develop a strategy that ensures that all diseases are given parity and that all people with a long-term condition in primary, secondary, tertiary and community or social care have their care effectively co-ordinated across multiple agencies. This is to ensure that people with long-term health conditions have co-ordinated care plans with effective communication between services and a single point of contact for concerns or questions.

HSSIB makes the following safety observation

Safety observation O/2025/067:

Health and care organisations can improve patient safety by allocating a point of contact for patients and/or their carers when people are discharged from services out of normal working hours. This will ensure patients and their carers are able to escalate any concerns relating to their ongoing care and drive improvements in care co-ordination.

1. Background and context

1.1 Introduction

1.1.1 This is one of five investigations that consider how working conditions in the NHS can be optimised to support patient safety, while maintaining and improving staff wellbeing (Health Services Safety Investigations Body, 2024a).

1.1.2 This section describes what is meant by long-term conditions, and the different models and definitions for care co-ordination. It includes background information about national work looking at how to support people's care needs, and relevant regional initiatives.

1.2 Long-term conditions

1.2.1 The National Institute for Health and Care Excellence (NICE) (2015a) defines a long-term condition as one that generally lasts a year or longer and impacts on a person's life. Examples include arthritis, asthma, cancer, dementia, diabetes, heart disease, mental health conditions and stroke. Long-term conditions may also be known as 'chronic conditions'. The term 'multiple long-term conditions' refers to the existence of two or more long-term conditions in a single individual (National Institute for Health and Care Research, 2021). The Office for National Statistics (2023) reports rising prevalence of long-term conditions in England.

1.2.2 Data from the Health Survey for England (NHS England, 2024b) revealed that 41% of adults and 17% of children had at least one long-term medical condition. In addition, research suggests that nearly 15% of people in England are currently living with two or more health disorders (Valabhji et al, 2023). A study from the University of Liverpool found that the number of adults living with more than two diagnosed long-term conditions increased by around 70% between 2004 and 2019, with a greater increase among individuals from the most deprived areas of England (Head et al, 2021).

1.2.3 For ease of reading, the term multiple long-term conditions (MLTCs) is used throughout this report to describe both people with long-term conditions and people with multiple long-term conditions.

1.3 Integration of care and care co-ordination

1.3.1 The language and terminology linked to integration of care and care co-ordination is varied. Many stakeholders have their own policy, definition and pathways to deliver integrated care and support care co-ordination. These documents include various terms for staff who may have a role in supporting how care is co-ordinated. Examples of job titles for such roles include:

- care co-ordinator (NHS England, n.d.a)
- carer champion (National Institute for Health and Care Excellence, 2020)
- care navigator (British Medical Association, 2023)
- key worker (NHS, 2024)
- lead professional (Department of Health, 2011)
- discharge co-ordinator (National Institute for Health and Care Excellence, 2015b).

The following section describes some of the different organisations' approaches to integration of care and care co-ordination, how organisations have defined care co-ordination and its implementation and research findings.

Department of Health and Social Care

1.3.2 In 2015 the Department of Health recognised the need for a system of integrated care for every person in England, meaning that care and support is built around the needs of the individual, their carers and/or their family. Its report, 'Integrated care and support: our shared commitment', referred to creating 'a culture of cooperation and coordination between health, social care, public health, other local services and the third sector … working in silos is no longer acceptable' (Department of Health, 2015).

1.3.3 A definition of integrated care and support was co-developed for the Department of Health (2015) by National Voices, and aligned with 'Making it real' (Think Local Act Personal, n.d.), through engagement with patients, people who use services and carers. The definition was intended to put the individual at the centre, around whom services should be co-ordinated:

"I can plan my care with people who work together to understand me and my carer(s), allowing me control, and bringing together services to achieve the outcomes important to me." (Department of Health, 2015)

1.3.4 In 'Major conditions strategy: case for change and our strategic framework', the Department of Health and Social Care (2023) stated that for people with major conditions 'a different set of services – including in areas like care co-ordination, symptom management and support for family and unpaid carers becomes more important'.

1.3.5 The UK government's mission for the NHS states that it wants to bring 'care closer to where people live, including through a new neighbourhood health service to deliver more proactive and personalised care' (UK Government, 2024).

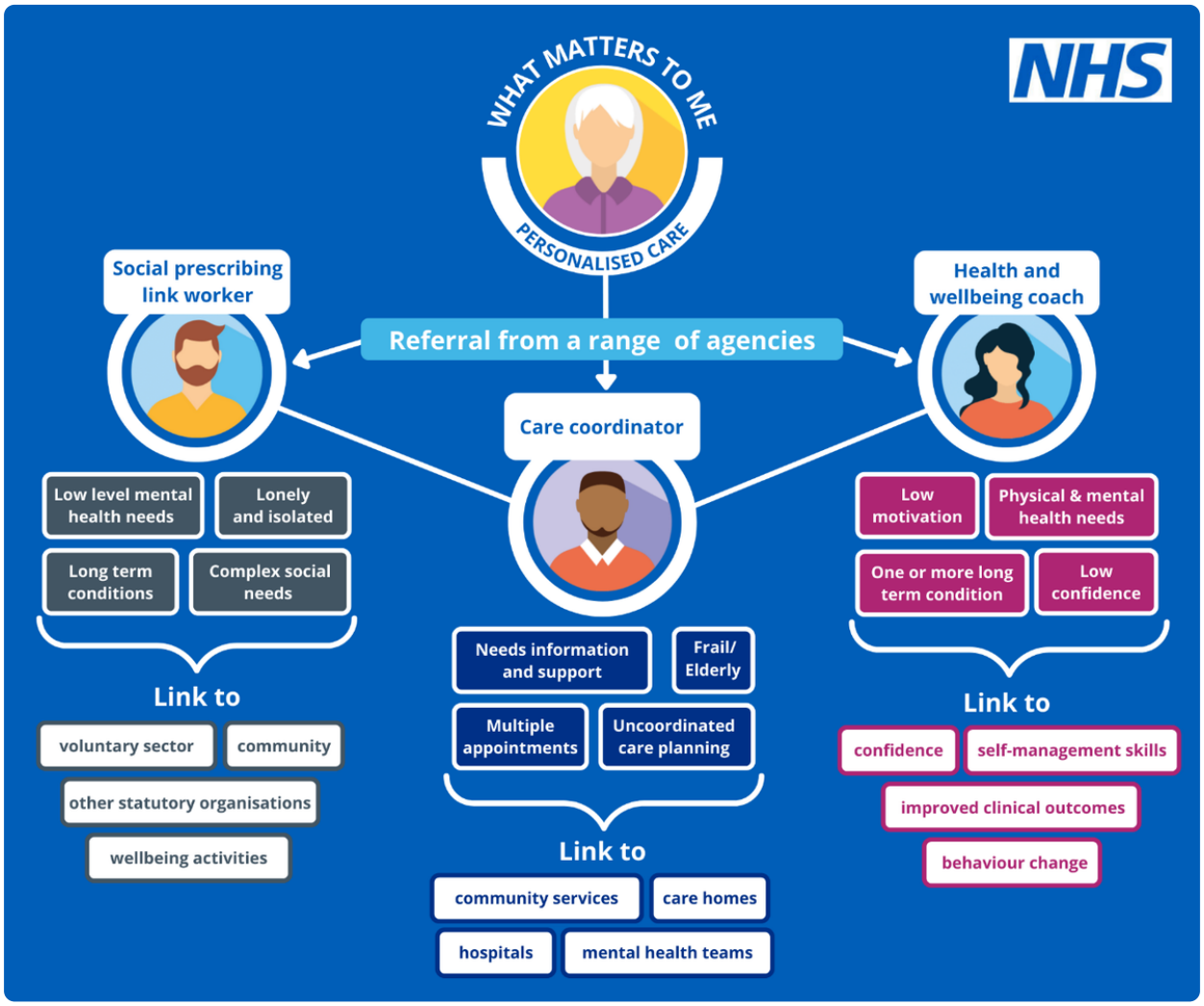
NHS England

1.3.6 NHS England defines care co-ordinators as follows:

'Care co-ordinators help to co-ordinate and navigate care across the health and care system, helping people make the right connections, with the right teams at the right time. They can support people to become more active in their own health and care and are skilled in assessing people's changing needs. Care co-ordinators are effective in bringing together multidisciplinary teams to support people's complex health and care needs.' (NHS England, n.d.a)

1.3.7 Figure 1 gives a visual representation of how NHS England views the role of care co-ordinators.

Figure 1 Role differences between care co-ordinators, social prescribing link workers and health and wellbeing coaches

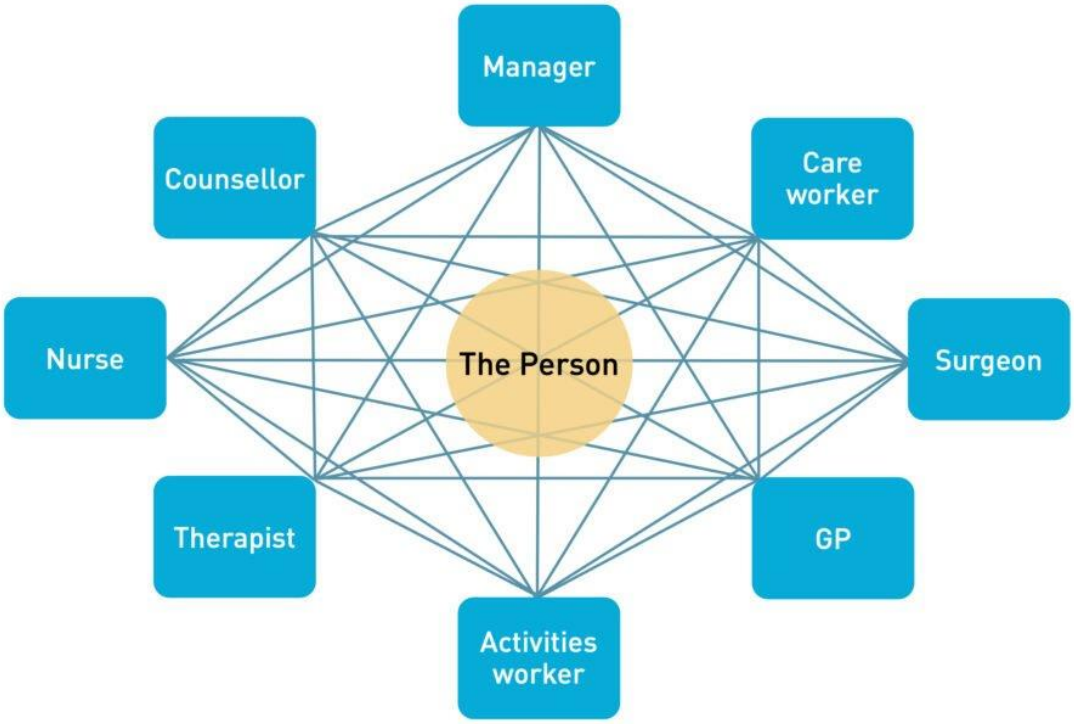


1.3.8 The NHS Long Term Plan (NHS England, 2019) includes an aspiration to improve care co-ordination through the development and use of primary care networks, integrated care systems, personalised care and proactive and preventative approaches.

1.3.9 The 'Workforce development framework for care co-ordinators' (NHS England, 2023) provides a framework for the standards and training of care co-ordinators. The training is accredited by the Personalised Care Institute, involves a 2-day course and signposts staff to 7 providers of care co-ordination training.

1.3.10 NHS England (2023) provides a visual representation of a typical system in which a person may be cared for (see figure 2) and explains that 'a person with complex needs may be getting health and care support from many different professionals, including nurses, counsellors, therapists, activity workers, GPs, surgeons, care worker and managers. Care co-ordinators help link all this care together'.

Figure 2 Representation of the network of services and professionals a person may need to navigate (NHS England, 2023)



1.3.11 The NHS has a Focus, Refer, Assess, Identify needs and Leave (FRAIL) strategy (NHS England, 2024a) which sets out 5 principles for the management of healthcare for frail people who access same day emergency care services (SDECs). Principle 5, 'Leave', relates to discharge and how to support people to be discharged as quickly as possible. It states that the provider (of the SDEC) should:

'Consider having a role in the service who links into primary and community services (such as by having access to GP records) to help with assessment and discharge planning.' (NHS England, 2024a)

1.3.12 The 'Neighbourhood health guidelines 2025/26' (NHS England, 2025a) set out a plan 'to move to a neighbourhood health service that will deliver more care at home or closer to home, improve people's access, experience and outcomes, and ensure the sustainability of health and social care delivery'. A key component of this is to ensure that people have co-ordinated care across multiple pathways and are given a care co-ordinator.

1.3.13 The National Institute for Health and Care Excellence (NICE) has produced a guideline which considers how person-centred social care and support for older people with social care needs and MLTCs should be planned and delivered (National Institute for Health and Care Excellence, 2015a). This guideline focuses on older people with social care needs and MLTCs and their carers.

1.3.14 In addition, NICE has published guidance on support for adults who provide unpaid care for anyone aged 16 or over with health or social care needs. The guidance aims to improve the lives of carers by helping health and social care practitioners identify people who are caring for someone and give them the right information and support (National Institute for Health and Care Excellence, 2020). This guidance refers to a carer champion:

‘A designated member of staff (for example in a GP surgery, hospital, workplace, leisure or similar setting) who is given the task of supporting and speaking up for carers. They can act as a key contact for carer information and advice in that setting, providing knowledgeable, expert advice as well as training other practitioners working within the service.’ (National Institute for Health and Care Excellence, 2020)

1.3.15 NICE clinical guideline 138 relates to improving the experience of care for people using adult NHS services, and states that:

‘For patients who use a number of different services (for example, services in both primary and secondary care, or attending different clinics in a hospital), ensure effective coordination and prioritisation of care to minimise the impact on the patient.’ (National Institute for Health and Care Excellence, 2012)

1.3.16 NICE (2015b) explores the transition between inpatient and community and care home settings. It states that a discharge co-ordinator ‘is a central point of contact for health and social care practitioners, the person and their family during discharge planning’. It also states that discharge co-ordinators should consider providing people with complex needs, their families and carers, with details of who to contact about medicine and equipment problems that occur in the 24 hours after discharge.

Care Quality Commission

1.3.17 The Care Quality Commission (CQC) recognises and reports that for many people, care is rarely about a single visit to a single service (Care Quality Commission, 2022). The CQC describes good care as:

‘… care that is based on individuals’ needs. It is care that seamlessly moves, for example, between GP, hospital, care home and back again. The care may be delivered by traditional services or by new models of care established to meet the nation’s changing health and care demands.’ (Care Quality Commission, 2022)

British Medical Association

1.3.18 The British Medical Association (BMA) understands that the task of care navigation (signposting people to the most appropriate clinician) is undertaken by care co-ordinators (British Medical Association, 2023). It provides guidance on how care co-ordinators could be employed in general practice, but this is focused on their role in general practice and not co-ordinating care across the health and care system:

‘Care navigation is a process done by care coordinators, appropriately trained reception or other practice staff, to signpost to the most appropriate clinician or elsewhere outside of the practice …

‘Care navigation and clinical triage allow practices to prioritise patients with the most urgent health needs, ensure they see the most appropriate clinician or are signposted to alternative services.’ (British Medical Association, 2023)

Transformation Partners in Health and Care

1.3.19 Transformation Partners in Health and Care is an organisation set up to share expertise and develop learning across the health and care system. It describes the role care co-ordinators within primary care networks as:

‘… advocates for specific groups of patients, such as people who are frail or living with severe mental illness. They support people to navigate their care journey and ensure those most affected by health inequalities can benefit from personalised care and support.

‘They coordinate information on patients at their GP surgery or surgeries and proactively find patients with complex conditions or needs who may benefit from extra support.

‘They are a main point of contact between these patients and the services involved in their care, supporting person centred decision making and streamlining information for both clinicians and the patient.’ (Transformation Partners in Health and Care, n.d.)

Research

1.3.20 There have been several research papers into care co-ordination spanning many years. One study suggested areas that need care co-ordination across healthcare systems and developed a plan for research, practice, and policy to address the challenges of co-ordinating

patient care with external providers (Hempel et al, 2021). The study recommended further research, practice and policy innovations in care co-ordination across multiple providers of care. Other examples of research findings in this area include:

- ‘The role of care coordinator for children with complex care needs: a systematic review’ (Hillis et al, 2016) stated: ‘Despite evidence that suggests that the role is pivotal in ensuring that care needs are sustained, there remains great variability in the understanding of the role of a care coordinator for this population.’
- Research (Khatri et al, 2021) emphasised the need for a way of understand evidence in a systematic way in the care co-ordination of health services and highlighted the importance of deliberate organisation of patient care activities among multiple people and organisations to facilitate appropriate healthcare delivery (Karam et al, 2021).
- The King’s Fund (2013) explored care co-ordination and described the lack of a common understanding of the role of a care co-ordinator. It also stated that there have been benefits to patients, carers and health, but that ‘success appears to be highly dependent on the way in which care co-ordination is implemented locally’.
- A study observing community-based multidisciplinary team (MDT) meetings (Douglas et al, 2022) revealed significant issues in care co-ordination. The research found that these meetings often lacked clear objectives and effective communication among healthcare professionals, leading to disjointed care plans for patients with MLTCs.
- A review examining the implementation of integrated health and social care services in Europe, including the UK (de Matos et al, 2024), identified persistent fragmentation. The study noted that despite efforts to integrate services, many patients experienced poor co-ordination, resulting in unmet needs and reduced quality of care.
- Other research has been undertaken to assess the effects of integrated care models in the UK and internationally (Baxter et al, 2018). This aimed to clarify the outcomes of these models and their applicability within the context of the NHS in the UK.

2. Patients’ and carers’ experiences

The investigation spoke to many patients and carers, on a one-to-one basis and in focus groups, to learn about their experiences of care co-ordination. Many of their experience were similar. The four vignettes that follow describe four examples of those experiences.

A child with a complex condition

2.1 A parent carer told the investigation about their child’s challenging health and care journey after being diagnosed with a life-limiting neurological condition.

2.2 The parent described a situation where their child had been prescribed anti-epileptic medication by a specialist hospital. The purpose of the medicine was to reduce the number and severity of their child's seizures. They were given enough medication for 10 days after the child's discharge from a hospital admission. Both the hospital and the parent had an expectation that the child's GP would be able to continue prescribing this medication.

2.3 However, the parents said that due to the medication being only "approved [licenced] for adults", the GP would not prescribe the medication. The tertiary hospital could prescribe it because of the rules within which the hospital operated. The medicine was working well for the child, but the parents felt "huge anxiety" that once the 10 days were up, the child would relapse, or in the worst case deteriorate further.

2.4 The child was also under the care of a consultant at their local secondary care acute trust for a respiratory condition. The consultant was aware of the tertiary care that the child was receiving. The parents, on advice from the tertiary hospital, asked if the consultant at the local acute trust could prescribe the anti-epileptic medicine. The acute trust could not do this either because it was not being in a position to support long term-medication for its patients for a condition that it was not actively managing.

2.5 The parents found themselves in a situation where they needed the medication, "which was having real benefit", but no one could prescribe it. The situation was eventually resolved by short-term prescriptions from the tertiary hospital, which has now become a long-term solution and continues with the tertiary hospital supporting the family.

2.6 Throughout the initial period of confusion over the medication, the parents spent a significant proportion of their time emailing and telephoning healthcare professionals and services to resolve their concern around the medication. This meant that they had less quality time with their child, created anxiety and frustration, and undermined their trust in the healthcare system. They found that no one was responsible for connecting the three services (GP, secondary acute and tertiary) or for carrying out the role of a holistic care co-ordinator so that the child received the care they needed. That role fell to the parents and they told the investigation that there was no "joined up thinking" across the health and care system.

2.7 They told the investigation they found similar challenges with connecting health and social care for their child's needs. Their role as care co-ordinator was problematic because health and social care staff used different words to mean the same thing. To get the response from health or care that they needed, they had to work out what answers staff in health and social care were looking for and "what language to use".

> “They are looking for key words – [such as the] difference between severe and profound – one is health and one is social. That was very difficult.”

2.8 The parents told the investigation that they were “exhausted” because of the effort they had had to put in over the years to connect services together, having to tell the same story over and over again, while having to provide care for their child.

> “… [our child’s] behaviour was so difficult during these times. She was very physically demanding and awake for hours and hours. This was a time we needed most support and had the least … Every parent … finds it difficult to negotiate [the health and care system] … you are exhausted because your child needs 24-hour care … [we] are the ones that constantly have to be on top of everything … [but could] reach the point of shall we even bother. Then the child is affected.”

2.9 The parents told the investigation that they felt that they were in a “privileged position” in that they could speak up, had learned to navigate the health and care system and still had the energy to do so. The parents said that they were aware of other parents in similar circumstances who were “running out of energy” or did not know who to contact next within health and care to get the right care for their child. They felt this would potentially be increasing the risk that their child would be missing a critical element of treatment or care. When asked if they feel heard as parents, they replied:

> “They are listening and learning but [there is a] high turnover of staff … It feels like ultimately a parent is managing a team of carers.”

An adult patient’s and carer’s experience

2.10 A man in his late seventies is the main carer for his wife. His wife, the patient, had multiple long-term conditions (MLTCs) that required primary, secondary and community care. The husband asked to speak to the investigation after going to a focus group organised by the investigation. The patient was unable to speak to the investigation.

2.11 The patient requires wound care for an open wound which has needed multiple hospital admissions. The patient’s MLTCs prevent her caring for herself and she is therefore reliant on others, including her husband, to deliver and manage her care and advocate for her. The husband told the investigation that “twice in 3 years … [the patient] has been harmed due to the

system not working together". At the time that the investigation met with the husband, the patient was on palliative care, with a plan for her care to be managed at home to avoid any further hospital stays.

2.12 The husband told the investigation that he had to regularly liaise with many health and care providers. These include the GP practice, the local community care trust, pharmacy, podiatry, psychiatry, social care and the local secondary care acute hospital. He has also had significant interactions with his local integrated care board when he has had a significant concern, or when he has become frustrated due to lack of cross-system support for his wife. The husband told the investigation that:

> "I am the [care co-ordinator] hub [for my wife]."

2.13 The husband explained that his role of care co-ordinator had placed a considerable burden on him, which led him to "feel overwhelmed". He said that because he needing to act as her "co-ordinator" he was unable to spend time with his wife as her husband. He also described having to administer medication and dress his wife's wound which caused her considerable pain. He described feeling "guilt in causing her pain".

2.14 The husband told the investigation that after a considerable length of time and much correspondence, the integrated care board had assigned the community matron to be the care co-ordinator for his wife, thus taking some burden off him. He felt that having a person nominated as his wife's co-ordinator represented the health and care system acknowledging the problem. Healthcare providers involved with the patient's care told the investigation that they acknowledged that care co-ordination was a problem but individual providers did not consider that it was their responsibility to resolve it.

2.15 The husband acknowledged that the assignment of the matron as his wife's care co-ordinator had come about because of significant correspondence. He felt that it was an individual solution rather than a system-wide change that would benefit other people in similar situations.

2.16 The husband said he was aware that "there are lot of us out here trying to look after complex patients" but that other patients may not have the same level of advocacy as he was able to provide for his wife. He thought that this could impact on their ability to get the care and co-ordination required.

A child's and parent's experience after transition to adult services

2.17 The parent is a working mum of two children. One of her children (the patient), now an adult, had MLTCs that required input from primary, secondary and tertiary care.

2.18 The parent told the investigation that care, including care co-ordination, for her son while he was a child (up to 18) was “excellent”. However, following transition to adult services, this experience was not the same.

2.19 The parent told the investigation that “no one” would take overall responsibility for her son’s care once he had transitioned to adult services and she found herself managing information flow between services, “chasing differences in advice [from different services] and acting as a hub [a co-ordinating function]”. She said that “it’s like a battle” and “very hard” with two children at home and balancing work and trying to manage her son’s healthcare and personal needs. She said that when she encountered problems, such as conflicting treatment and care advice from different services, she was “too busy dealing with the situation at hand [managing her son’s care]” to report the problem of conflicting information.

2.20 The parent’s overall experience of her son’s care as an adult is that there is “no one to co-ordinate care apart from the parent”.

A patient’s experience

2.21 The patient is a middle-aged professional working man who suffered a stroke. He received hospital care to treat and manage his healthcare needs, made good progress and was discharged with “hope” that things would be getting better. He was very complimentary about the inpatient care that he received and believed that level of care would continue after discharge.

2.22 His stroke left him with additional healthcare needs, needing regular contact with neurology, cardiology, occupational therapists and physiotherapists, GPs and community nursing teams, among other health and social care professionals.

2.23 He said that these multiple agencies “all operate in their own silos” and not as a team, and that “there was nobody to create that team [a cross-system team aware of all his health and care concerns]”. The way that he and his wife cope with this situation is that they “manage the team” to connect the individual parts of the system and get the care he needs.

2.24 The patient describes himself as being a “dot in the middle of a wider system”. Each part of the system (individual health and care pathways and providers) are focused on that dot. That focus is intense but the various parts of the system do not look to either side of themselves or across the whole system to see if his care is being co-ordinated. He said that he is:

> "… a lay person on a lot of this stuff [different services]. I had to educate myself, so I was kind of educating myself whilst trying to organise it, [it feels like] pushing this big rock up a hill to get it [connecting and co-ordinating different services] sorted… We've got some amazing people [in healthcare]. They're kind of hidden away in little nooks and crannies and you know, they're in their own little cabins. So you don't know that they're there. So it's only when you stumble on them you realise they are there."

2.25 The patient said that it takes significant effort to maintain the right level of care that he needs and when a person was not "well this becomes more difficult."

> "There is no one single person who can connect me to all the services that I may need [now and in the future]."

3. Analysis and findings

The investigation engaged with primary and secondary care providers and integrated care boards to understand how people get the care they need across providers and during transition of their care. It also engaged with national bodies to understand the challenges they faced in delivering care co-ordination policy.

The need to build personalised care capacity and capability into the workforce, to optimise outcomes for people and populations, is recognised by NHS England (n.d.h). All organisations talked openly of challenges in co-ordinating care for patients with multiple long-term conditions (MLTCs) and the workforce resources to do this well. There was consistency in the challenges mentioned by the providers, which centred on communication between organisations, and where and how responsibilities passed between them.

Through its analysis of the evidence gathered, the investigation explored care co-ordination in the following themes:

- care co-ordination
- impact on people when care is not co-ordinated.

3.1 Care co-ordination

3.1.1 This section explores the national, regional and local perspective of care co-ordination and how it is delivered operationally.

National perspective on care co-ordination

3.1.2 The investigation found many national health and care organisations were able to describe the benefits of the care co-ordination role. However, the health and care system has not been able to implement such a role that interconnects patients with MLTCs to the multiple services that provide them with care, or provides a central point of contact for future needs and queries.

3.1.3 A national UK survey suggested that a wide range of patients, parents and carers do not have co-ordinated care, with findings indicating limited access to care co-ordinators, specialist centres and care plans (Walton et al, 2023).

3.1.4 The NHS England 'Workforce development framework for care co-ordinators' (NHS England, 2023) sets out benefits for people and the health and care system. For example:

- A named contact to go to with questions and requests for information who will check on people to see how they are doing.
- A contact who understands all of a person's health and care needs and what is important to them.
- Support to understand the health and care system and get access to the right services and resources at the right time, for example personal health budgets.
- Reducing stress and anxiety for those who have difficulty understanding what is happening or accessing the services they need.

3.1.5 People who need care co-ordination told the investigation that NHS England's (n.d.a) description of care co-ordination (see 1.3.6) is what they would "love to happen". The investigation heard from patients and carers that if this role was implemented as it is written by NHS England, it would significantly ease the burden of care co-ordination on them.

3.1.6 The NHS England (2025a) neighbourhood health guidelines state that 'there will need to be multidisciplinary coordination of care for population cohorts with complex health and care or social needs who require support from multiple services and organisations'. The Department of Health and Social Care (DHSC) told the investigation that this aligns with its strategic direction for neighbourhood working (see 1.3.5). NHS England said that as part of a multidisciplinary team "allied health professionals (see glossary) are well placed to lead and support these roles [care co-ordination] and often because of the nature of their roles already coordinate care in communities for long term conditions associated with therapy, for example, Parkinsons disease, Multiple Sclerosis and other neurological pathways and also in Children and Young people's care."

3.1.7 NHS England told the investigation that “in an efficient, fully integrated system, care co-ordination is [should be] occurring by default and a specific task for co-ordination should not be needed”. The investigation was also told by NHS England that “patients and carers believe that [the] NHS is a monolith and that information and care is transferred seamlessly … [but] that the system is fragmented”.

3.1.8 The DHSC told the investigation that it is committed to moving toward a “neighbourhood health service” which will deliver more care locally to create healthier communities, spot problems earlier and support people to stay healthier and maintain their independence for longer. Neighbourhood Health Guidelines (NHS England, 2025a) were published alongside the 2025/2026 priorities and operational planning guidance (NHS England, 2025b) and the Better Care Fund policy framework 2025 to 2026 (UK Government, 2025) to help local authorities and health care providers to continue progress neighbourhood health in 2025/2026 in advance of the publication of the 10-Year Health Plan, which would have primary, community and social care in one facility.

3.1.9 The DHSC told the investigation that “it is too early to say exactly what the plan will look like – it is important that we listen to what the public and health and care staff say is most important to them – but what is certain is that delivering the three shifts will be central tenets of the plan. The 10 Year Health Plan will describe a shared vision for the health and care system in 2035, drawing directly from the extensive engagement underway with the public, patients and staff.”

3.1.10 A collaboration between the DHSC and the NHS (Change NHS) stated that there is the intent to shift care from hospitals to the community, which would mean resourcing community and social care services. This would include looking at the different healthcare roles needed to deliver this model of care, including how care is co-ordinated (Change NHS, n.d.).

3.1.11 A senior manager in the DHSC said that:

“The approach of extending care and treatment into communities consist of multidisciplinary specialist teams, to ensure co-morbidities are properly managed and place a minimum burden on the individual to engage with the NHS. However, the multidisciplinary approach must have parity to ensure some conditions (such as respiratory diseases) are not overshadowed by other conditions (such as cancer or CVD [cardiovascular disease]). The triage process of individual patients to specialist teams also needs a parity-based approach, so that conditions are not deprioritised.”

3.1.12 The investigation heard that care co-ordination for MLTCs is important; however, any further development of care co-ordinator roles and strategy at regional level should ensure that there is parity for all MLTCs.

3.1.13 An article written by the Chief Medical Officer for England stated that:

'… good vertical integration exists … for a single condition or disease, but there is little or no horizontal integration between diseases that often coexist. This will require an intellectual shift and rethinking some elements of our research, training, and practice in virtually every discipline.' (Whitty et al, 2020)

The investigation heard from healthcare professionals and people who use healthcare services that care co-ordination for a single pathway, for example diabetes, can be co-ordinated well, but that for MLTCs the pathways are not integrated resulting in multiple appointments for different conditions. This is explored further in the report (see 3.1.33).

3.1.14 The Royal College of General Practitioners (RCGP) told the investigation that "there is a fine balance between care co-ordination and who holds responsibility for overall patient care … care co-ordination does not mean in charge of the patient". The RCGP said that it understood the role of care co-ordinators to be administrative rather than clinical, although the person in the role may be a clinician.

3.1.15 The National Institute for Health and Care Research (NIHR) highlighted that individuals with MLTCs often face difficulties due to uncoordinated care. Patients reported challenges in managing complex treatment regimens and navigating between various healthcare providers, leading to increased burden and potential deterioration of health (National Institute for Health and Care Research, 2021).

3.1.16 The organisations above, and many more, understand the benefits to patients of care co-ordination, and recognise that care can be co-ordinated for single health care pathways. However, as described in section 2 of this report, for people with MLTCs care co-ordination can be fragmented or non-existent across the multiple services they may need.

Terminology relating to care co-ordinators

3.1.17 Care co-ordinators are referred to in several guidance documents, in various ways (see 1.3.1), and the role may relate to specific pathways such as discharge from hospital or in a GP practice. Hillis et al (2016) discuss the use of different language such as 'Family Care Coordinator, Care Coordination Counsellor, Nurse Care Coordinator, and Key Worker' but that there is no consensus on the language or the purpose of the roles (see section 1.3). The Department of Health (2011) produced an information sheet that described the various terms that may be used to refer to care co-ordinators, including, key worker and lead professional. In addition, the investigation heard that some GP practices have care navigators.

3.1.18 Many people told the investigation that the different titles that care co-ordinators can have causes confusion. The investigation heard that this variation in language may mean that care is not easily accessible.

3.1.19 As an example, the National Institute for Health and Care Excellence (NICE) uses the phrase ‘carer champion’ in guidance (see 1.3.14). None of the carer experiences shared with the investigation recognised the role of a ‘care champion’, but carers stated that such a role would have been useful to help with care co-ordination.

3.1.20 The investigation found that the multiple terms and variation in terminology around care co-ordination can create confusion for patients and carers and for staff in the health and care system.

Regional and local perspectives on care co-ordination

3.1.21 There are several examples of care co-ordination services described on NHS provider websites, which can include:

- helping patients have more control over their own care
- linking patients to social care
- helping patients to communicate with health and social care services and acting as an advocate
- helping to understand the complexities in the health and care system
- referring patients to non-medical services such as financial support and fire services.

3.1.22 Guidance such as NICE (2020) and NHS England (n.d.e; 2024a) focuses on care co-ordination in specific pathways. However, it is limited in terms of integrating the care of people who may have MLTCs that cross more than one care pathway. This means that care co-ordination is specific to a disease pathway but not across the system.

3.1.23 The investigation spoke to a small number of integrated care boards (ICBs) about care co-ordination. They said that they had competing priorities, such as commissioning and assuring services, and this meant that they did not have the capacity to put care co-ordination services in place. They also said that there were challenges in designing an integrated system across providers because of the different ways in which they operate and communicate with each other (Health Services Safety Investigations Body, 2024b: 2025b).

3.1.24 ICBs and healthcare providers told the investigation that integrated care systems (ICSs) (see glossary) were formed to integrate healthcare and social care services, with the intention of improving communication and resource sharing. The investigation heard about challenges

associated with ICSs and that the way that they worked was based on relationships rather than clear lines of accountability and responsibility (Health Services Safety Investigations Body, 2024b; 2025a; Healthcare Safety Investigation Branch, 2023b).

3.1.25 The ICB responsible for the care of one of the patients whose story was shared in section 2 acknowledged that it had created an individual solution for the patient and her carer. However, this was a one-off arrangement to meet the specific needs of the patient based on multiple concerns, complaints, continual emails, phone calls and visits from GP practice staff and ICB staff. The ICB told the investigation that the reason that care co-ordination could be challenging is that "the way in which staff have different work patterns, and the fact that care is being provided by different organisations at different times, one single route for contact … [is] not possible".

Organisations that support the delivery of care co-ordination

3.1.26 Several organisations have identified that there is a gap in care co-ordination for the people they represent. These organisations are mainly in the charity sector or research-led projects.

3.1.27 To address some of the care co-ordination concerns that it has identified, Age UK (2024) has developed a programme called 'Personalised Integrated Care'. The intention is that an older person can be assigned a care co-ordinator who then assesses the person's needs and then connects healthcare, social care and voluntary services so that people can get the right care at the right time. The investigation found that this programme was developed along very similar principles to the NHS England (n.d.a) definition of care co-ordination (see 1.3.6).

3.1.28 Age UK states that:

'Although not quantified, the support provided by the Personal Independence Coordinators (PICs) has released time from primary care. It has improved the quality and coordination of care, as well as facilitating timely access to care. It has also helped to shift conversations away from a purely medical model of care.' (Age UK, 2024)

3.1.29 The Carers Trust (2025) has developed the 'Triangle of Care', which considers the needs of mental health service users, carers and health professionals. It is a 'therapeutic alliance between carers, service users and health professionals. It aims to promote safety and recovery and to sustain mental wellbeing by including and supporting carers'.

3.1.30 The Triangle of Care is based on six key standards including: 'A carer introduction to the service is available, with a relevant range of information across the care pathway.' NHS England further developed this model of care into other areas of healthcare, such as dementia (NHS England, 2016). The investigation was told by some providers that they have signed up to

a Triangle of Care model which ‘means that carers are included at all levels of care, giving equity in the service user journey. Using the Triangle of Care will help promote safety, support recovery and improve wellbeing’ (NHS England, 2016).

3.1.31 The Systems and Process Redesign and Optimisation at Childhood Key Events and Transitions (SPROCKET) project (University College London, 2025) is an initiative that is looking to ensure children and young people with MLTCs are connected with health and social care and education to ensure that they and their carers have the right support for them across the health and care system. The SPROCKET team told the investigation that the project was needed because the health and care system can be “daunting” for people to navigate, particularly those who are already in a difficult situation. They said that people could become ‘lost to the system’ and would miss vital care when their circumstances and care needs changed, for example because of a change in health, social, family, education or moving house. The project is currently in its development phase but early indications are that there is significant benefit to children and young people and their carers.

3.1.32 The investigation found that all the projects or initiatives described above are demonstrations of different organisations developing their own methods of ensuring that people with MLTCs get the care co-ordination that they need.

Care co-ordination in GP practices

3.1.33 Patients and carers told the investigation that before they needed to use healthcare services they believed that the healthcare system was joined up. They assumed that carers or patients would not be responsible for chasing results and appointments, and thought that information would be transferred between secondary care, primary care and community care. They found the reality was starkly different in that it was the patients and carers who had to co-ordinate their care.

3.1.34 Patients and carers described themselves as being the person in the centre (“hub”) (see figure 2) and said that care co-ordination as described in policy and guidance does not happen in reality. Patients and their carers told the investigation that they are the care co-ordinator, and no single person or organisation undertook this function.

3.1.35 The investigation heard that there are hubs for specific health conditions that intend to improve care for people with those conditions (NHS Providers, 2024). A GP said that care co-ordination can happen around them but without involving them. Examples included a cancer pathway and women’s health hub, whereby care for that specific need was co-ordinated but the GP was not fully informed about their patients’ ongoing holistic care needs.

3.1.36 In a Healthcare Safety Investigation Branch (2023a) investigation, GPs said that they frequently saw patients who had both health and social care needs. Patients would book appointments with them to discuss social care concerns because they did not know where else to go.

3.1.37 The investigation visited GP practices and spoke to staff in care co-ordinator roles. These were predominantly administrative staff, but in some cases they were healthcare assistants or from other healthcare roles. They told the investigation that they helped patients in their GP practices to attend for annual medical reviews, blood tests and other care needs. They sometimes visited vulnerable patients in their home, in particular those who had difficulty attending appointments or may have missed several important medical appointments, to understand the reasons for non-attendance. The care co-ordinators all said that they did not have a responsibility to co-ordinate care across community, primary care, secondary care or tertiary care but could assist in the referral process to different or additional services.

3.1.38 One care co-ordinator in a GP practice said that they were the only care co-ordinator in the practice. They said that they helped people from more vulnerable groups, such as older people or patients with dementia. They worked with patients to help them understand how digital tools may help them to access GP services, or to self-manage certain conditions such as high blood pressure, asthma or diabetes using a digital application. They also linked patients to social prescribers (see glossary and figure 1) in the practice and asked patients if they were known to social services, and could make referrals if needed. They said that if a patient had a carer this would be recorded in their notes, but they recognised that carers find it “difficult to co-ordinate their own and someone else’s care”, which in turn could lead to future health problems. They said that if there was another care co-ordinator in the practice they could expand their tasks to look at hospital discharge, which currently was not possible due to capacity challenges. An additional care co-ordinator could create follow-up appointments so that people could get the care needed and potentially “prevent readmission [to hospital]”.

3.1.39 In many cases, patients and carers reported that there were staff shortages (in primary and community care), which increased the reliance on carers to give medication, carry out wound care and other care tasks. Healthcare staff explained that increasing demands on their services meant that there was a focus on the operational delivery of services, taking away time to establish and maintain management functions such as care co-ordination. In many cases patients and carers said they did not have a nominated care co-ordinator.

3.1.40 A GP practice told the investigation that it had tried to put together an easy-to-read document explaining the care pathway for patients with dementia, including contact numbers and ways to access services. The GP practice went on to say that the system was so complex that it was unable to bring together all the information. It stated: “We are healthcare professionals and we can’t do this, so how can patients cope?”

Care co-ordination in other healthcare settings

3.1.41 The investigation explored the role of care co-ordinators in other healthcare settings, for example mental health and secondary care. A care co-ordinator in secondary care told the investigation that they were primarily concerned with co-ordinating care for a specific condition or disease. If a patient had MLTCs they would be referred to a different service by a GP or hospital doctor and their care for that particular disease would be co-ordinated by a different care co-ordinator. So a patient with MLTCs might have several care co-ordinators to speak to, in their GP practice and in hospital, for each specific disease/condition they were receiving care for (Whitty et al, 2020).

3.1.42 A mental health care co-ordinator told the investigation that they were focused on helping their patients with finances, housing concerns, getting support at home and reintegration into society. They said that they did not have a responsibility to co-ordinate care across primary or community care, particularly if it was for a physical health condition. A GP told the investigation that when a patient is discharged from mental health services the GP becomes the care co-ordinator. The GP gave an example of a patient recently discharged from mental health services who had visited the GP practice for an appointment related to their mental health needs. The GP asked the patient “who is your care co-ordinator?” and the patient responded that they no longer had a care co-ordinator and it had reverted to the GP for any ongoing health concerns. It is well known that people with mental health problems may have physical health needs that cross many healthcare pathways (Royal College of Psychiatrists, 2025).

3.1.43 NICE guidance (2015b) discusses the role of a discharge co-ordinator and their ability to connect health and social care organisations to support safe discharge from hospital. This includes a point of contact for patients and carers for 24 hours after discharge to answer any concerns that patients may have. However, the patients and carers that the investigation spoke to were unaware of discharge co-ordinators or that they could contact them after discharge.

When people are discharged from secondary care

3.1.44 A common concern shared with the investigation by patients, carers, GP practices and community care services was around discharge from secondary care outside primary care working hours (typically after 18:30 hours Monday to Friday and at weekends (see glossary)). Patients said that they did not know who to contact or what to do if there was a concern.

3.1.45 The investigation was told by many people that patients and their carers were so busy when preparing to go home, or anxious about the transition to home life after a hospital admission, that it was easy to miss information, such as:

- Who was their point of contact out of hours to assist with prescriptions if they ran out.
- When their next follow up appointment was.

- That they had not been given a care plan, or if they had, it had not been explained fully or they were “not in the right frame of mind” to take the details in, and therefore did not understand it when they got home.
- Who to contact if they needed advice on their care plan.

3.1.46 Patients and carers also told the investigation that there could be a lack of equipment provided by the hospital at discharge to undertake care in a patient’s home, for example wound dressings. Patients and carers told the investigation there was an assumption that the “community nurses” would do this but when they could not, they had no one to contact to resolve their concern. This could cause confusion about who would provide this equipment, especially outside normal working hours.

3.1.47 Age UK said that it frequently hears of people being discharged at the weekend and not given any information, or being given medication to take home but not being aware of when or how to take it. Age UK told the investigation that being discharged from hospital can be a stressful time for older people. It said that older people in the community or in other care settings do not always know who to contact if they have a new or ongoing healthcare need.

HSSIB makes the following safety observation

Safety observation O/2025/067:

Health and care organisations can improve patient safety by allocating a point of contact for patients and/or their carers when people are discharged from services out of normal working hours. This will ensure patients and their carers are able to escalate any concerns relating to their ongoing care and drive improvements in care co-ordination.

Information flow and care co-ordination

3.1.48 Throughout the investigation, one of the main challenges to care co-ordination that the investigation heard about was the difficulties in sharing patient information (Health Services Safety Investigations Body, 2024c). Many healthcare staff, patients and carers told the investigation that the “system [is] broken” and that there is “no transfer of information [between providers]”. The second workforce and patient safety investigation, focusing on the use of digital tools for online consultation in general practice (Health Services Safety Investigations Body, 2024a), looked at this issue in more detail.

3.1.49 Healthcare professionals described the challenges in information sharing. Digital patient records could not be viewed across primary, community, secondary and tertiary care because information technology systems are unable to “talk to each other”. They also said that

sometimes they were unsure whether patient information could be shared as it was “protected information”. This was a particular problem when trying to share information between health and social care.

3.1.50 The investigation heard in all the GP practices that it visited that it can take several weeks for discharge letters to reach a GP. The NHS Standard Contract requires discharge letters to be issued within 24 hours of discharge for an inpatient stay, day case or emergency department attendance (NHS England, 2024d). This means that when a patient needs care from their GP before the discharge letter arrives and is uploaded on their system, the GP must take a history from the patient or carer and is reliant on this verbal information to make decisions about care. There is a gap in knowledge at this time.

3.1.51 One carer told the investigation they were given medication to take home from an acute hospital. A week’s supply was given, with the intention that the GP would prescribe it thereafter. This instruction was contained within the discharge letter which arrived several weeks after the patient was discharged. However, in the interim the GP prescribed the medication at a different dose which caused confusion. The carer had to spend a significant amount of time telephoning the hospital and GP and trying to connect them so that they could agree the amount of medication to give.

3.1.52 Patients and carers described that when they asked questions relating to care, there was “no feedback once a question is submitted, so we don’t know what is going on”, requiring additional phone calls to chase care plans.

3.1.53 Many patients and carers had a view that health and care organisations were “not working together” with “too many people going around in a circle” and not providing an answer to a problem. They felt that this was because health and care staff could only work within the structures of their organisation. Health and care staff told the investigation that they knew what needed to be done (provide co-ordinated care) but they did not have the influence or ability to resolve concerns.

3.1.54 NHS England told the investigation that they have responsibilities regarding data and clinical record sharing (NHS England, 2025c). They said that they have “taken steps to increase access to clinical records and improving capability to co-ordinate information across agencies.” NHS England also said that they have supported the development of ‘shared care records’ through the work done on the National Care Record Service (NCRS) (NHS England, 2025d). The NCRS aims to provide a “quick, secure way for health and care workers to access national patient information to improve clinical decision making and healthcare outcomes.” NHS England said that the steps to improve access to clinical records and the NCRS would provide tools to “support the care co-ordinator in delivering the responsibilities of the role successfully.”

3.1.55 The investigation found that poor information sharing and flow can create gaps in knowledge for healthcare professionals so that making decisions is more challenging. This can create a potential safety issue. Several Healthcare Safety Investigation Branch investigations have identified these concerns, including:

- Harm caused by delays in transferring patients to the right place of care (Healthcare Safety Investigation Branch, 2023b)
- NHS 111's response to callers with COVID-19-related symptoms during the pandemic (Healthcare Safety Investigation Branch, 2022)
- Electronic prescribing and medicines administration systems and safe discharge (Healthcare Safety Investigation Branch, 2019).

What care co-ordination means to patients and carers

3.1.56 The NHS Long Term Plan (NHS England, 2019) states that there are relatively high levels of care co-ordination. However, the investigation heard significant challenges with care co-ordination, and poor care co-ordination was a key issue raised at the focus groups held as part of the investigation's information gathering.

3.1.57 All the patients and carers that the investigation spoke to had a common perspective on what care co-ordination meant to them. It included:

- having a single point of contact for health and social care to avoid having to spend time contacting multiple services
- engagement with a care co-ordinator that feels meaningful, and that they are talking to a person who has access to all of their patient record so that they do not have to retell their medical "story"
- enjoying more time with the people they care for
- time to relax or take a short break between physical caring tasks and not having to co-ordinate care
- not having to tell a patient's story repeatedly to different services
- minimising frustration because someone is helping them
- trust and confidence that patients are getting the care they need.

3.1.58 Patients and carers said that without care co-ordinators they spend a significant portion of their time connecting services "who seem unable to talk together". The lack of health and care system integration was a constant factor throughout the investigation. It was described by some people that where efforts were made by organisations to support offering patients and/or

carers advice and guidance, sometimes that included a contact number; however, this would go to an automated answering service with time “wasted” listening to the message and no one returning the call.

3.1.59 Many people the investigation spoke to referred to having to get care from various specialists and services, leading to a more complex care pathway. They described that this led to care that felt “fragmented” and referred to examples of poor communication between providers and services (see section 2).

3.1.60 The investigation heard from carers who described the challenges that arose when the people they cared for needed support from social care services, which were not well integrated with NHS care. These integration challenges have led to gaps in support.

Summary

3.1.61 The investigation found that NHS England’s definition of care co-ordinators is what patients and carers want, but that there is variability in its application across the health and care system.

3.1.62 Variability in the roles and responsibilities of care co-ordinators, the way care co-ordinators are employed in practice and the terminology used causes confusion for patients and carers. The investigation found that care co-ordinator roles were focused within GP practices or for a single clinical pathway, and not across multi-agency or health and care pathways, and not applied as intended in the NHS England (2023) framework. There is a difference in how the health and care system views the role of care co-ordinator and how it should be carried out, and what happens in practice.

HSSIB makes the following safety recommendation

Safety recommendation R/2025/059:

HSSIB recommends that NHS England/Department of Health and Social Care, working with other relevant organisations, reviews and evaluates the implementation of the care co-ordinator role. This is to ensure that all patients with long-term conditions have their care co-ordinated and that they have a single point of contact 24 hours a day, 7 days a week, to help them with any queries or concerns that they may have.

3.2 Impact on people when care is not co-ordinated

3.2.1 The investigation spoke to several people as part of focus groups and individually. Common themes arose relating to patient and carer distress and harm caused by lack of care co-ordination. Many people told the investigation about the anxiety caused by not being able to find the right person to talk to about care, creating feelings that they were “alone” in the system (Carers UK, 2023).

3.2.2 Patients and carers told the investigation that they become frustrated when having to continually tell their medical history over and over again when put in contact with a new service, or when talking to new people in a service they have used previously. They felt that if their care was being co-ordinated by a central organisation this would be reduced. They told the investigation that the retelling of a patient’s story can be traumatic and can take a significant amount of time – time that could be used to manage treatment plans and so on.

3.2.3 Carers and the charity Carers UK told the investigation that carers often have to carry out physically demanding tasks, throughout the day and at night, including lifting a person in and out of bed, personal care, giving medication or attending to dressings. Carers UK said that these day and night tasks could be needed over long periods of time, meaning that the carers themselves could develop physical and mental health concerns that they did not have time to address. Carers UK said that the additional “burden of trying to find the right person to talk to [about the person they were caring for]” could create additional stress, thus compounding any ongoing carers’ health concerns. It also said that this ultimately had an impact on the person being cared for.

3.2.4 Many carers described the extreme tiredness caused by having to care for a patient with MLTCs, co-ordinate their care and spend time on phone calls with many clinicians and social workers in order to get what the person being cared for needs (Carers UK, n.d.). Many described being “overwhelmed by how much is needed [to be] done”. They also said that they felt “burnt out” after years of caring and co-ordinating care, and worried about “how much longer I can go on”.

3.2.5 Children with rare MLTCs may need long-term health and care support. The experience described by patients and carers in section 2 links with research into care co-ordination for children, which states that patients and carers ‘spend a lot of time coordinating appointments, communicating between providers, clarifying social legal issues, and more’ (Willems et al, 2023).

3.2.6 Several carers told the investigation that through their social network they were aware of other carers in similar situations. In many cases they saw that some of these carers did not always get the right care needed because they were not able to articulate the needs of the person they were caring for. The investigation heard that “he who shouts loudest gets the care”

was a consistent factor in carers getting the right care needed. Many people did not know how to raise care co-ordination concerns, did not know who to contact to help them, or did not want to bother anyone for something they felt they should be able to resolve themselves. Some carers get to the point that they “just accept” that the system is what it is.

3.2.7 Throughout the investigation, patients, carers and stakeholders told the investigation that without the dedication and effort that carers put into managing patients’ care, appointments and connecting services across health and care systems, patients would not get the care they need. However, many carers were concerned about “who looks after the carers when they can’t carry on” and said that carers are “supposed to be valued, but aren’t”.

3.2.8 Age UK told the investigation that many older people are living with many conditions. It said that “even when older people are in a closed setting [one where a patient is being closely cared for] that care co-ordination is difficult”.

3.2.9 Age UK said that older people can feel “lost and frustrated” because they are unable to access the right care, and that many give up trying to access care because they “just don’t know who to contact”. This may lead to worsening physical health which can bring about isolation and a deterioration in their wellbeing. In turn, this can result in increased hospitalisation when “people could have been cared for at home if they had been given access to a care co-ordinator who would know who to connect them with”.

Summary

3.2.10 The benefits of care co-ordination can be felt by both patients and carers. These include fewer administrative tasks for carers and patients, more time focusing on caring for patients, reduction of the stress and burden associated with co-ordination of health and care, and reduction of missed appointments.

3.3 Conclusion

3.3.1 While there is an ambition to build personalised care capacity and capability in the workforce, to optimise outcomes for people and populations, there remains significant variability in its implementation.

3.3.2 The investigation found that there is significant support for the role of care co-ordinators across national and local organisations and all recognised the benefit that they could have for patients. However, there was variation in how the role of care co-ordinators interpreted by the health and care system and employed in practice across primary, secondary and tertiary care, with no single centralised care co-ordination function that was able to span all areas of health and care for people with MLTCs.

3.3.3 Several national and local organisations had care co-ordination programmes that were attempting to address the challenges in this area. These were driven by locally identified needs or focused only on community care. These programmes attempt to provide a system that includes effective communication and information sharing between multiple services, integrating health and social care, and have people in roles who are empowered to make connections across the health and care landscape.

3.3.4 Patient and carers can experience harm, frustration and lack of trust in the health and care system because of poor care co-ordination. What matters to them and their individual needs are not always supported.

HSSIB makes the following safety recommendation

Safety recommendation R/2025/060:

HSSIB recommends that the Department of Health and Social Care works with NHS England and other stakeholders, to develop a strategy that ensures that all diseases are given parity and that all people with a long-term condition in primary, secondary, tertiary and community or social care have their care effectively co-ordinated across multiple agencies. This is to ensure that people with long-term health conditions have co-ordinated care plans with effective communication between services and a single point of contact for concerns or questions.

4. References

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5. Appendix: Investigation approach

To identify topics for investigation within the workforce and patient safety theme, the investigation reviewed intelligence from service and professional regulators, national reports, the Parliamentary Health and Social Care Select Committee, academia and research. Discussions also took place with a large number of national stakeholders to understand their emerging concerns in this area. As a result of this work four investigations were launched in June 2023 looking at temporary staff, the digital environment and care co-ordination.

Evidence gathering

The investigation's findings were drawn from analysis of available intelligence (research and policy literature) and through activities undertaken by HSSIB (observational visits, patient and staff interviews, wider stakeholder interviews and focus groups).

Stakeholder engagement

Specific stakeholders engaged with primarily for this investigation are shown in table A and listed below.

Table A Patients and families, providers and regional stakeholders engaged with primarily for this investigation

Patients and families	Providers/staff	Regional oversight
Patient and carer focus groups	Staff in primary, secondary and tertiary care	Integrated care boards (ICBs): 40 ICBs in the overall workforce and patient safety theme 3 ICBs spoken to with specific focus on this investigation
Interviews with patients and carers with lived experience	Staff in community settings	3 integrated care systems
	Charities	
	Universities undertaking research into care co-ordination or other related areas	

The investigation directly engaged with the following national stakeholders and academics as part of the investigation:

- Department of Health and Social Care – general practice and community teams
- NHS England – nursing directorate, primary care team
- service regulators – Care Quality Commission
- professional bodies – Royal College of General Practitioners
- charities – Age UK, Carers UK, Carers Trust.

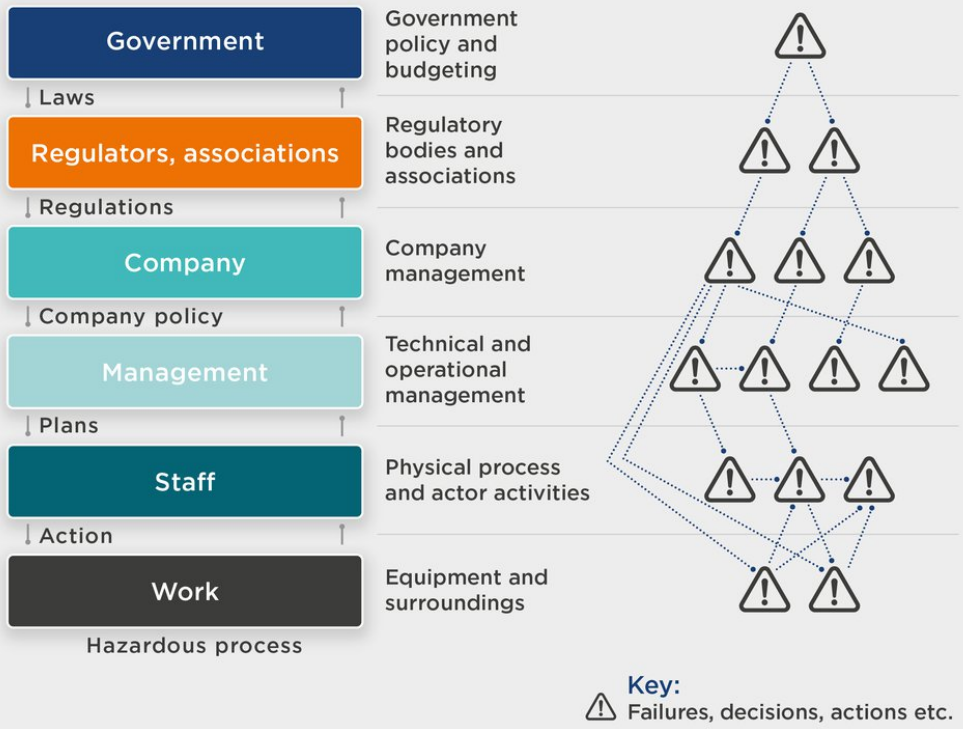
Further stakeholders were also engaged with during the consultation phase for this report.

Analysis of the evidence

The findings presented in this report were identified following triangulation of various evidence sources and following consultation with stakeholders involved in the investigation. The AcciMap model (Svedung and Rasmussen, 2002) was used to inform the investigation approach to help understand risks across local, regional and national boundaries. The model focuses on identifying relationships between the different levels of the health and care system, which include government policy and budgeting; regulatory bodies and associations; local area management; physical processes and actor activities (what staff, people, organisations, systems did); and equipment and surroundings. The contributory factors are arranged into a

series of levels representing the different parts of the health and care system. The investigation's analysis focused on identifying connections between the different levels of the system (see figure A).

Figure A The AcciMap model



6. Glossary

Allied health professional	In England, the term AHPs refers specifically to art therapists, drama therapists, music therapists, chiropodists/podiatrists, dietitians, occupational therapists, operating department practitioners, orthoptists, osteopaths, paramedics, physiotherapists, prosthetists and orthotists, radiographers, and speech and language therapists (Institute of Health and Social Care Management, n.d.).
Community health services	Services that support people with complex health and care needs to live independently in their own home for as long as possible (NHS England, n.d.b).
Digital applications (apps)	Technology to help health and care professionals communicate better and enable people to access the care they need quickly and easily, when it suits them (NHS, n.d.f).

Discharge co-ordinator	A single health or social care practitioner responsible for co-ordinating a person's discharge from hospital (National Institute for Health and Care Excellence, 2015b).
General practitioners (GPs)	Medics who treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment (NHS, n.d.).
Integrated care boards (ICBs)	NHS organisations that are responsible for planning health services for their local population. There is one ICB in each integrated care system area (see below) (NHS England, n.d.d).
Integrated care systems (ICSs)	Partnerships that bring together NHS organisations, local authorities and others to take collective responsibility for planning services, improving health and reducing inequalities across geographical areas (The King's Fund, 2022).
Long-term conditions (LTCs)	A long-term condition is one that generally lasts a year or longer and impacts on a person's life (National Institute for Health and Care Excellence, 2015a).
Multiple long-term conditions (MLTCs)	Multiple long-term conditions refers to the existence of two or more long-term conditions in a single individual (National Institute for Health and Care Research, 2021).
Multidisciplinary team (MDT)	A group of professionals from one or more clinical disciplines who together make decisions about recommended treatment of individual patients (NHS England, 2024c).
Out of hours	Contractually, the out of hours period is between 18:30 and 08:00 hours on weekdays, and from 18:30 hours on Friday to 08:00 hours on Monday including bank and public holidays (Royal College of General Practitioners, 2019).
Personalised care	Personalised care represents a new relationship between people, professionals and the wider health and care system. It happens when people make the most of the expertise, capacity and potential of people, families and communities. Personalised care is based on 'what matters' to people and their individual strengths and needs (NHS England, n.d.h).
Primary care	Primary care services provide the first point of contact in the healthcare system, acting as the 'front door' of the NHS. Primary care includes general practice, community pharmacy, dental, and optometry (eye health) services (NHS, n.d.c).
Primary care networks (PCNs)	Groups of GP practices working closely together, along with other healthcare staff and organisations, to provide integrated services to the local population (British Medical Association, 2024).
Same day emergency care (SDEC)	SDEC allows specialists, where appropriate, to assess, diagnose and treat patients on the same day of arrival at hospital who would otherwise have been admitted to hospital (NHS, n.d.e).

Secondary care	Sometimes referred to as ‘hospital and community care’, can either be planned (elective) care such as a cataract operation, or urgent and emergency care such as treatment for a fracture (NHS Providers, 2025).
Social prescribers	Social prescribing connects people to activities groups, and services in their community to meet the practical, social and emotional needs that affect their health and wellbeing (NHS England, n.d.g).
Tertiary care	Tertiary care refers to highly specialised treatment such as neurosurgery, transplants and secure forensic mental health services (NHS Providers, 2025).
Transition of care	Transition of care refers to the various points where a patient moves to, or returns from, a particular physical location or makes contact with a healthcare professional for the purposes of receiving healthcare (World Health Organization, 2016).

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