

From boundary object to boundary subject; the role of the patient in coordination across complex systems of care during hospital discharge

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1 From boundary object to boundary subject; the role
2 of the patient in coordination across complex systems
3 of care during hospital discharge

4

5 **Abstract**

6 Advocates for patient involvement argue that seeking the active contribution of
7 patients and families in the coordination of care can help mitigate system
8 complexity, and lead to improvements in quality. However, sociological and
9 organisational research has identified barriers to involving patients in care
10 planning, not least the power of, and boundaries between, multiple professional
11 groups. This study draws on literature from Science and Technology Studies
12 (STS) to explore the patients' role in coordinating care across professional-
13 practice boundaries in complex care systems. Findings are drawn from a two-
14 year ethnographic study (including 69 qualitative interviews) of hospital
15 discharge following hip-fracture care, and describe the changing role of the
16 patient as they move out of hospital into community settings. Findings describe
17 how 'the patient' plays a relatively passive role as boundary object while
18 recovering from surgery within hospital, where inter-professional coordination
19 was prescribed by evidence-based guidelines, leaving little space for patient
20 voice. As discharge planning begins, patient involvement is both encouraged and
21 contested by different professional groups, with varying commitment to include
22 patient subjectivities in care. As patients move into home and community

1 settings, they, their families and carers play an increasingly active role in
2 coordination, often in light of perceived gaps in coordination between care
3 providers. This paper argues that whilst the need for patient and carer
4 involvement is becoming increasingly evident, such involvement plays into, and
5 is mediated through, existing relations between professional and practice
6 groups. Patient and carer involvement is therefore not straightforward and
7 should be considered across the health and care systems in order to
8 meaningfully improve care quality.

9

10 **Keywords**

11 United Kingdom

12 Boundary objects

13 Coordinated care

14 Patient involvement

15 Professional boundaries

16 Professions

17 Complexity

18

19

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25

1 **Introduction**

2 Research shows that care quality depends on the coordination of many
3 professionals working within and across organisational boundaries (Weinberg et
4 al, 2007; Moore et al., 2003). Although coordinated or integrated care is a
5 longstanding policy concern, the challenge of coordination is increasingly
6 interpreted as rooted in the complexity of care systems (Braithwaite et al, 2017).
7 This view suggests that care is routinely organised through large numbers of
8 heterogeneous groups cooperating in non-linear patterns of interaction, rather
9 than through relatively well-defined, linear pathways. Integral to the sociological
10 analysis of these complex systems is the persistence and influence of social
11 boundaries between interacting groups, and how these exacerbate system
12 complexity through complicating inter-professional or organisational
13 interactions.

14

15 In this context, there have been calls for more active patient involvement as a
16 basis for improved cross-boundary coordination (O'Hara and Lawton, 2016;
17 Ellins et al., 2012). Specifically, patients and families are identified as the sole
18 consistent presence across the times, spaces and relationships of complex care
19 systems. This therefore makes them ideally placed to act as the fulcrum around
20 which services are organised, especially for helping to coordinate care across the
21 professional and organisational boundaries that are shown to shape care
22 processes. Drawing on organisational theory, patients and families might be re-
23 cast as 'boundary spanners' (Williams, 2002), given their unique position to
24 manage the interface between different occupations and organisations,
25 especially to support communication and coordination amongst disparate

1 groups. Research shows, for example, patient involvement in care planning and
2 integration can lead to improvements in clinical outcomes and patient
3 experience (Dyrstad et al., 2015; Flink et al., 2012).

4

5 While patients' involvement has a strong normative appeal, a wealth of
6 qualitative and quantitative studies suggest there are enduring limits to patients'
7 ability to adopt a coordinating role (Joseph-Williams et al., 2014). Prioritising
8 patients' subjective experiences stands against dominant biomedical evidence,
9 rooted in objectivity and quantification at the aggregate level; patient views are
10 therefore only partially and problematically incorporated into clinical decision-
11 making (May et al., 2006). Evidence-based medicine - marshalled into healthcare
12 practice through the proliferation of bureaucratic technologies such as clinical
13 guidelines, decision tools, checklists and performance indicators - requires
14 clinical professionals to adopt increasingly standardised practices (Timmermans
15 and Berg, 1997). Standardisation shapes not only the work of individual
16 professionals, but also forms the basis of cross-boundary working, itself
17 dependent on routine and typification. Highlighting this, Allen's work (2014a;
18 2018) identifies the role of 'translational mobilisation'; the transformation of
19 people into organisationally recognised patients, reconciling their divergent
20 needs with systems, resources and care pathways. Clinical work, Allen argues, is
21 increasingly constituted by the efforts of translating patients across parallel
22 bureaucratic systems within and across organisations. As such, the status of
23 patients as both the agents and objects of coordination is far from clear.

24

1 To further explore the role of patients (as agents and objects) in the coordination
2 of care across professional and organisational boundaries we bring together
3 sociological literature on professional and organisational boundaries with
4 Science and Technology Studies (STS) work on boundary objects. That patients
5 themselves could be considered boundary objects has been noted elsewhere, yet
6 the implications of this for the organisation of care have yet to be explored
7 (Nicolini, et al., 2012). The concept of the boundary object provides a basis for
8 exploring how coordination is achieved through contrasting forms of patient
9 objectification across professional and organisational boundaries. Through
10 ethnographic study of hospital discharge, we find that patients' role in the
11 coordination of care shifts from being relatively passive within the tightly
12 organised hospital environment to becoming relatively active as they move out
13 of the hospital into loosely organised community and domestic settings. In doing
14 so, we highlight gaps in current systems of coordination, not straightforwardly
15 addressed through patient involvement. We also extend theoretical study of
16 objects during scientific and professional coordination by outlining how the
17 patient plays a varied role as boundary-object, boundary-subject and boundary
18 spanner, with movement between these different roles reflecting professional
19 and organisational struggles over their care.

20

21 **Boundaries and boundary objects in the coordination of care**

22 Boundaries have been the focus of considerable attention across the social
23 sciences (Lamont and Molnár, 2002). In the field of health and social care,
24 boundaries are often described in relation to the division of expert labour,
25 especially the jurisdictional boundaries within and between professions (Abbott,

1 1988; Waring and Latif, 2017). The sociology of professions identifies how the
2 creation, maintenance and disruption of social boundaries – boundary work – is
3 intrinsic to the constitution of discrete professional jurisdictions within a
4 competitive system of expert labour (Abbott 1988; Gieryn, 1983; Ehrich et al.,
5 2006). Professional boundaries have been shown to cause fissures in patterns of
6 knowledge sharing (Currie et al, 2007), the spread of innovation (Ferlie et al,
7 2005) and care practice (Dixon-Woods, 2010).

8

9 At the meso and micro levels, professional boundaries interact with
10 organisational boundaries, creating divisions between communities of practice
11 (Lave and Wenger, 1991). Within organisational research, boundaries between
12 such professional-practice groupings have been considered around three
13 overlapping domains (Ferlie et al., 2005). First, boundaries of knowledge, with
14 professions defining themselves by specific forms of expertise. This is
15 exemplified by the difference between the hierarchy of bio-medical evidence
16 prioritised in acute medicine, against the deliberative and situated
17 understandings valued in social care (Webb, 2001). Second, boundaries of
18 identity and culture, including the extent to which professional groups value
19 inter-professional decision-making or prioritise patient involvement in their
20 own care (Dent and Whitehead, 2013). And third, boundaries of organisation
21 including the established routines, rules, resources, and divisions of labour
22 present in professional organisations (Timmermans and Berg, 1997).

23

24 From a STS perspective, the boundaries within and between expert groups and
25 their implications for knowledge production have been a central concern. The

1 boundaries between science and non-science, for example, have provided the
2 impetus for research on 'boundary work' (Gieryn 1983), and of particular
3 relevance to this study, the concept of 'boundary objects'. Star and Griesemer
4 (1989) identify boundary objects as 'things' that have divergent meanings and
5 uses for the different social groups, but which maintain sufficient common
6 identity to provide the basis for collaborative endeavour. Star and Griesemer
7 (1989) identified repositories (library catalogues), ideal types (blueprints),
8 objects with coincidental boundaries (maps) and standardised forms as common
9 objects in scientific enquiry that enables specialist to coordinate their distinct
10 activities.

11

12 Qualitative research has elaborated various forms boundary objects can take
13 (Fox, 2011; Swan et al., 2007), the processes by which they foster, or limit,
14 collaboration (Oswick and Robertson, 2009) and the relationship between
15 objects, boundaries and social worlds (Bechky, 2003; Swan et al., 2007). For
16 instance, theories (Fox, 2011), phrases (Brand and Jax, 2007), and practices
17 (Owens, 2015) have all been interpreted as boundary objects with variable
18 implications for collaboration. Within healthcare, Allen's (2009; 2014b) research
19 examines collaboration between professional, managerial and service user
20 groups in the process of developing new care pathways. This finds participants
21 using considerable political and organisational skill to design pathway tools
22 (boundary objects) that afford space to negotiate tensions between professional
23 groups. Keshet et al., (2013) demonstrate how multiple boundary objects allow
24 'loose collaboration' across the social-structural and epistemic boundaries
25 between alternative and conventional medicine, highlighting in particular the

1 importance of epistemic 'fit' between objects and the wider institutional
2 environment.

3

4 There has been less consideration of how people, or human bodies, act as
5 boundary objects. This is perhaps surprising given the analytic equivalence
6 afforded to human and non-human entities within Actor Network Theory and
7 STS. A notable exception is Mol's (2002) examination of how patients' bodies and
8 diseases are enacted heterogeneously in the everyday performance of cross-
9 disciplinary medical work, with different versions of disease rendered knowable
10 through the application of multiple technologies and fields of medical
11 knowledge. Here, the body acts as a boundary object for professional-practice
12 groups, as their distinct forms of practice 'hang together' through their
13 pluralistic enactment of the body, related to their own technologies and practices
14 of work. Although this demonstrates the essential role of the patient as a central
15 object in coordinating healthcare work, Mol's work focuses on the hospital
16 environment, rather than the contribution of the patient to coordination across
17 complex systems of care.

18

19 It is worth recognising that examining the patient as a boundary object could
20 appear contradictory to the aspirations of the patient involvement movement,
21 i.e. holding patients as passive objects of professional practice. However, as
22 Timmermans and Almeling (2009) argue 'objectification' serves a variety of ends
23 for patients as well as for professionals and organisations. Medical advancement
24 depends upon professional specialisation, increasingly fragmenting the body
25 into constituent elements. This, Timmermans and Almeling (2009) argue, can be

1 experienced as alienating, empowering or restorative, depending on whether the
2 patient feels involved in the care process and/or whether treatments are felt to
3 lead to improved experiences of health and wellbeing. As Cussins (1996)
4 illustrates in the context of infertility treatment, patients may in fact
5 demonstrate agency through participating in self-objectification as they actively
6 seek to improve their chance of successful reproductive outcome. Further
7 discussed by Prentice (2003), professional socialisation involves taking on
8 distinct professional cultural rules on acceptable 'object formation' whilst
9 avoiding problematic 'objectification'.

10

11 This suggests that rather than a clear division between patients as passive
12 objects of care, or patients as active agents, we should instead look for different
13 forms and implications of objectification, especially at the intersection of
14 different professional boundaries, where varying interests, knowledge and
15 practices are involved in the coordination of care. For example, we can identify a
16 comparatively 'narrow' understanding of ailments or body parts fitting with the
17 knowledge of higher status and more specialised medical and surgical groups
18 (Prentice, 2013), and broader or 'holistic' understandings of patients amongst
19 lower status therapists and social care communities (Finlay, 2001). However, the
20 implications of these different care 'objects' on coordination are yet to be
21 considered. This study investigated how professional groups engage in such
22 object formation, to consider the patient's role in coordinating across boundaries
23 in complex care processes.

24

25

1 **Coordinating Hospital discharge**

2 The challenges of coordinating care across professional boundaries is
3 exemplified by hospital discharge; the transfer of care from the hospital to a
4 community setting (Aase et al., 2017; Glasby et al., 2008). The transfer of patients
5 between care settings is widely recognised as a vulnerable and high-risk stage in
6 the patient journey (Forster et al. 2003; Moore, et al., 2003; Kripalani et al.,
7 2007a). Prominent threats to safety including problems with medicine
8 reconciliation, managing wounds and infections, and continuity of care (Burke,
9 2003; Grimes et al., 2008; Kripalani et al., 2007b; Waring et al. 2013). The threats
10 to safe hospital discharge are often rooted in the complexities of coordinating
11 care across professional boundaries. As patients move out of hospital, care
12 responsibilities pass between professional groupings (e.g. hospital clinicians and
13 community social workers), between organisations, (e.g. acute and community
14 hospitals), between care sectors (e.g. health and social care), and between
15 economic sectors, (e.g. from the public to not-for-profit or private sector).
16 Ethnographic research on discharge pathways reveals significant contradictions
17 and limitations in the social organisation of care (Wells, 1997), including conflict
18 between the needs of individual patients and the multiple bureaucratic systems
19 through which their care is organised. Hospital discharge is therefore a critical
20 case to examine the patients' role in coordination across professional boundaries
21 within complex systems of care.

22

23 **Methodology**

24 This paper draws upon the findings of a two-year ethnographic study of the
25 social organisation of hospital discharge. Taking an ethnographic approach

1 allowed for direct observation and 'thick' description of the locally important
2 elements of discharge planning and care transitions, which were interpreted in
3 terms of the social and cultural boundaries that shaped the social organisation of
4 hospital discharge. All relevant ethical approvals were obtained through the UK
5 NREC prior to research commencing.

6

7 The ethnographic study was undertaken in two regional care systems in the
8 English National Health Service (NHS). Each system was organised around a
9 medium-sized English city with a single NHS Trust providing acute care; in
10 excess of 20 NHS primary care providers (General Practitioners); and between
11 two and four community NHS hospitals and rehabilitation services. Each system
12 also involved social care commissioners and providers, in the form of local
13 authority (municipal) 'social services', and a large range of public, private and
14 third sector social care providers.

15

16 Within each of these care systems, the study focused on the discharge of patients
17 receiving inpatient hip replacement surgery and physiotherapy, followed by
18 community-based on-going physiotherapy and other rehabilitation care. Hip
19 fracture was chosen as a condition predominantly affecting frail older people
20 who often have multiple co-morbidities including both physical and cognitive
21 impairment (Giusti, et al., 2011). As such, discharge planning is often complex,
22 involving consideration of past and future long-term health and social care
23 needs. Care for hip fracture patients requires a wide range of acute and
24 community specialists to work in close cooperation (Tierney and Vallis, 1999),
25 including orthopaedic and orthogeriatric medical teams, nursing groups,

1 therapists and social care providers. Readmission rates are relatively high, and
2 previous studies have shown the period following hip fracture present
3 challenges for organising safe and effective ongoing care (O’Cathain, 1994).
4 Finally, hip fracture services in the UK have been subject to national policies to
5 standardise care pathways, including guidelines for multi-disciplinary care and
6 are therefore an appropriate site to investigate coordination across professional-
7 practice groups.

8

9 Data were collected (2011-2013) through qualitative interviews and non-
10 participation observations of discharge planning and care transitions over a two
11 year period. Approximately 120 hours of observations were undertaken over a
12 two year period, focusing on the temporal and spatial organisation of daily work
13 (schedule of ward rounds, meetings, handovers, discharge times); identifying key
14 events and activities (MDTs, drug rounds); identifying key individuals or groups
15 ascribed with knowledge sharing roles (discharge co-ordinators, clinical leads).
16 In addition, semi-structured interviews were carried out with staff (69 staff
17 interviewees across the hip fracture pathway, see table 1). Interviews with staff
18 lasted on average 45 minutes and explored participants’ role, the routines and
19 experiences of coordinating with other staff groups, the processes of hospital
20 discharge and perceived risks and challenges. The study also ‘followed’ the
21 discharge journeys of 17 patients, including interviews at up to three time points
22 (once in hospital and two times up to six week after discharge).

23

24

INSERT TABLE 1 ‘Interview respondents’ ABOUT HERE

25

1 Interpretative qualitative data analysis was undertaken to develop descriptive
2 and contextualised understanding of cross-boundary work and its contribution
3 to discharge. This involved an iterative process of close reading of data, coding,
4 constant comparison, elaboration of emerging themes and re-engaging with
5 wider literature. Themes were developed through first independent open coding
6 by both members of the research team on samples of the data, with initial codes
7 used to code the rest of the data, with additional codes added and refined at
8 regular intervals during the analysis process. As the coding process progressed,
9 thematic categories were identified. While the study was oriented to investigate
10 issues of coordination across boundaries, the current focus on the patients'
11 boundary role emerged only through data collection and analysis, becoming
12 evident in light of limitations of other mechanisms of coordination.

13

14 **Findings**

15 In both study sites, the work of managing discharge was dispersed across
16 multiple professional and occupational groups (**see Table 2**). Differences in the
17 knowledge, culture and organisation of these professional-practice groups made
18 discharging patients a continual challenge. Commonly discussed boundary
19 challenges included discordant IT systems, incompatible performance measures,
20 varying tolerance of risk as well as differences in hierarchy, governance, work
21 patterns and practices. To highlight the contribution of the patient in
22 coordination between groups, we describe their role during three stages of
23 discharge 1) post-operative ward care, 2) preparation for discharge and 3) post-
24 discharge community care. Each of these points involved different forms of
25 professional-practice coordination, moving from 'tightly knit' coordination

1 immediately prior to discharge, to looser and more open-ended forms of
2 coordination as the patient moved out into the community. This placed changing
3 requirements for coordination on the patient as they moved through the care
4 pathway.

5

6 **INSERT TABLE 2 'Professional-practice groups routinely involved in**
7 **discharge activities' ABOUT HERE**

8

9 **Ward based care: patient as boundary object**

10 Within both hospitals, immediate post-operative care was located in specialist
11 orthopaedic wards, where care pathways were underpinned by the national Hip
12 Fracture Database audit. Audit measurements were regularly cited by staff as
13 structuring their work, and prescribed specific care requirements for each
14 professional group. National audit was overlaid with local contracts that set an
15 11-day 'target maximum' length of hospital stay, driving staff to progress
16 patients rapidly towards discharge.

17

18 *'if you look through the pathway, [Physiotherapy] are identified early on, i.e.*
19 *the patient comes in through Accident and Emergency, they are hopefully*
20 *operated on between twenty four and thirty six hours, ideally twenty four*
21 *and then the further following day is when we introduce ourselves to the*
22 *patient, get them up and progress them.'* (Lead Physiotherapist)

23

1 Key profession-practice groups involved at this stage were orthopaedic
2 surgeons, who monitored patient recovery from surgery through daily ward
3 rounds; orthogeriatric physicians who specialised in the wider physical health of
4 patients; and ward nurses and therapists who supported on-going patient
5 recovery and early physiotherapy. These groups worked in close proximity,
6 sharing the same ward spaces, nursing desk, equipment rooms, computer
7 terminals and rest areas, and were in regular communication throughout the
8 working day, especially through structured ward-based activities such as the
9 ward round, handover meetings and weekly MDT [multi-disciplinary team]
10 meetings.

11

12 *'Well, we discuss at morning handover and MDT, but we see [OTs and PTs]*
13 *on the ward each day, we know them. The doctors you bleep them and*
14 *generally you would see them on the ward daily and you can say can you see*
15 *such and such'* (Ward Nurse)

16

17 As noted in the literature, points of disagreement between professional-practice
18 groups were evident in everyday care, such as the readiness of a patient to
19 commence certain therapies. Overall however, there was a sense of a dominant
20 'script' with mutual understanding of how roles and responsibilities for ward-
21 based care were distributed and accomplished. Groups were quick to pull each
22 other up on incomplete tasks or comment on the quality of communication
23 processes of other groups.

24

1 *'We increasingly noticed, and we worked with nursing staff, that the*
2 *morning handovers weren't as good as they could be, so we developed a new*
3 *tool that has to be signed so everyone knows [the nursing shift] is up to*
4 *speed'* (Orthogeriatrician)

5
6 At this stage, the patient played a relatively passive role in inter-professional
7 coordination, representing a prominent common object around which multiple
8 professional-practice groups choreographed their work. This was well
9 illustrated in weekly MDT meetings in which patient care was reviewed and
10 discharge plans developed through scripted inter-professional interactions. For
11 each patient, a professional representative reported progress on their aspect of
12 care, for example weight-bearing status (physiotherapist), bone recovery
13 (surgeon), presence of infection (nurse), or engagement with living tasks
14 (occupational therapist). Although each articulated a different ontology of the
15 patient (Mol, 2002) based on distinct professional knowledge domains, the
16 cumulative reports of each professional group representative could contribute to
17 a shared understanding of the patients' progress along the care pathway.

18
19 **Lead nurse:** *'Next is Mr Jones, bay 2 bed 3, three days post-op, still not up,*
20 *any progress?'*

21 **Physiotherapist** *'I've been this morning, still very little movement, he's*
22 *really weak'*

23 **Orthopaedic doctor'** *It was a complex hemiarthroplasty, there wasn't*
24 *much good bone to go into [...]'*

1 **Occupational therapist** *'he actually seemed better today, we had a good*
2 *chat but yeah...'*

3 **Lead nurse:** *'OK so can we monitor and full report back on Thursday?' Next*
4 *is Mrs Ahmed [...]*

5

6 Significantly, the physical presence of the patient in the ward bed provided a
7 point of orientation. In both hospitals, for example, patient progress was
8 recorded on interactive 'smart' boards, but there were only used intermittently.
9 Instead, clinicians observed (often at a distance) patients occupying ward beds
10 as a more immediate visual indicator of care progress, workload and resources
11 availability, with clinicians often pointing at their patients from behind the
12 nurses' desk when discussing on-going tasks.

13

14 In descriptions of their hospital stay, patients often discussed themselves as
15 willing to accept their position as compliant recipients of care akin to Parson's
16 (1951) sick role. Although overall judgment of hospital care varied dramatically
17 across participants, they typically described themselves as seeking to cooperate
18 with the 'good' or 'bad' care provided by health professionals, rather than
19 actively coordinating their care.

20

21 *'It's hard when this time arrives, you know, when you're getting poorly [...] I*
22 *have nothing really to complain. People are very kind. Very kind. The nurses*
23 *as well have got good patience.'* (Female patient)

24

1 *'I'm determined to get better and if these people [hospital staff] want to put*
2 *some effort into it, I will go along with them. I can't say more than that can I?'*

3 (Male patient)

4

5 **Preparing for discharge: patient as contested boundary subject**

6 Following initial stages of post-operative care and early rehabilitation, ward staff
7 began preparing for discharge. Patients assessed as 'good' or 'well', i.e.
8 responding positively to treatment, were discharged three to four days following
9 surgery. Those assessed as 'difficult' or 'poorly' were assessed as requiring more
10 attention to their physical and psychosocial well-being, resulting in a long and
11 more complicated route to discharge. Specifically, the discharge of more
12 complicated patients involved daily challenges for staff that ranged from
13 ensuring the physical suitability or 'readiness' to leave the hospital, as well as
14 arranging the appropriate levels of on-going care in community settings.
15 Arranging on-going care was often made difficult by the lack of resources in the
16 community (e.g. rehabilitation beds, home equipment supplies, care workers),
17 and difficulties in coordinating with external agencies (e.g. communication
18 breakdowns, misaligned working patterns).

19

20 *'In theory we should be able to move everyone out within 10 days regardless*
21 *[...] I said in theory, but there are a million things that go wrong'*

22 (Physiotherapist)

23

24 Once the patient was assessed as recovered from surgery, the primary
25 responsibility for their care was transferred from surgeons to ward-based

1 medics, nurses and therapists. These clinicians seemed determined to maintain a
2 strong 'production' focus including throughput of patients.

3

4 *'Our role is as an acute hip fracture service. Immediate recovery, not long-*
5 *term rehabilitation.'* (Discharge Liaison Nurse)

6

7 *'if the patient refuses to go, so you can be still stuck in, the patient is in day*
8 *seven and they have agreed to get a bed, day eight, so the wrong hospital.*

9 *So they get stuck. We should be able to kick them out'* (Physiotherapist)

10

11 In comparison with the immediate stages of post-operative care, the division of
12 responsibilities for discharge planning was more ambiguous, exacerbated by
13 inter-group tensions over the appropriate level of patient involvement in
14 assessments and care planning. Depending on the intended discharge
15 destination, staff involved in discharge planning needed to navigate a multi-
16 faceted boundary infrastructure, including overlapping and repetitious paper-
17 based forms, legal standards, communication channels and information
18 technologies. For example, referrals from the acute hospital to social services
19 involved completing physical and mental health assessments, followed by a two-
20 stage notification process and a funding decision tool.

21

22 *'The Continuing Healthcare Checklist [CHC] is filled out, which is a checklist*
23 *to see whether this patient will be [funded by] health or social, and then you*
24 *fill out section two, which is an entire form to say the patient will require*
25 *social services. [...] And then they will send that off as section five and the*

1 *social services have to respond within twenty-four or forty eight hours.'*

2 (Physiotherapy Lead)

3

4 Responsibility for completing bureaucratic tasks was often discussed, with
5 accusations of 'buck passing' either between shifts or between professional-
6 practice groups.

7

8 *'There's pressure on us because at the MDT, if it's suggested, like last*
9 *Tuesday, 'Right. These three patients need CHC, Section Twos have been*
10 *identified. They need a package of care. We're now on their eight day of the*
11 *pathway.' We then go to the meeting today and that CHC hasn't been done.*

12 *"Why hasn't it been done?" (Ward Nurse)*

13

14 *'So it's always when you've got the [bed availability] piece of paper, it's*
15 *always the last person to sign it is the rotten egg' (Occupational Therapist)*

16

17 For busy (and more junior) ward nurses, engaging patients in technical
18 assessments was a daunting and time-consuming task, for which they often had
19 not received training. It was often seen as more straightforward to collect the
20 required information through desk-based 'detective work'. It was surprising to
21 observe, for example, how nurses often used patients' residential postcodes to
22 access 'street view' on Google Earth to answer questions on patients' homes,
23 such as access arrangements. Other assessment forms were required by
24 legislation to be completed alongside patients and carers, including cognitive and

1 health funding assessments. Junior nurses, and those less familiar with the
2 referral system, often found 'active' patient engagement difficult to realise.

3

4 *'the big thing from discharge paperwork that is a bit of a nightmare like I*
5 *say is the CHC. We have to do it with either the patient or a family member.*
6 *Some of the nursing staff are nervous about doing that because it's talking*
7 *about the patient's cognitive ability, behavioural issues and actually facing*
8 *them outwards with the relatives - they feel quite intimidated'* (Lead Nurse)

9

10 In contrast, occupation therapists and orthogeriatric doctors appeared more
11 enthusiastic about interacting with patients and families to develop personalised
12 care plans. These groups were often observed during handovers and MDT
13 meetings advocating for family meetings to discuss care plans with patients and
14 families. This was criticised by other clinical groups as 'holding up' discharge and
15 disrupting patient throughput.

16

17 *'we have the background, we have to learn about mental health within our*
18 *training so we tend to be quite holistic. We tend to look at those things that*
19 *other people don't necessarily see'* (Occupational Therapist)

20

21 *'you think the patient is nearly ready, as good as they will get, and then*
22 *[OTs] get involved and suddenly there are hundreds more things that we*
23 *need to sort out'* (Physiotherapist)

24

1 From the accounts of professionals, as well as patients and family, patients'
2 engagement with the discharge planning process varied markedly, not least due
3 to varying cognitive function. Patients and families did not necessarily recognise
4 the benefits of participating in the assessment processes, and often described
5 participation as bureaucratic and repetitive.

6

7 *'Well they went through it all with us. Took a bloody age actually, we had to go
8 through all of these forms and tell them what we thought about this and that.*

9 *That one [Nurse] was nice though'* (Female patient)

10

11 *'A lot of the patients cannot understand why you're actually there and why you
12 need to do these assessments with them.'* (Occupational Therapist)

13

14 What appeared important to patients was not necessarily the degree to which
15 they participated in care planning, which could equally be described as a burden,
16 but whether they felt they had received appropriate and well-coordinated care.

17

18 *'From half-past five in the morning to strip my bed and I was sitting on a chair
19 from that time till I got home. It had gone eight o'clock at night. I felt like I
20 wanted to cry because, you know, I felt they just didn't care.'* (Female patient)

21 **Post discharge: patient as reluctant boundary spanner**

22 Following hospital discharge, care journeys became exponentially more diverse
23 as patients dispersed to multiple settings dependent on their wellbeing and
24 personal circumstances, i.e. home, care home, rehabilitation centre, or
25 community hospital. Approximately one third of patients went on to

1 rehabilitation facilities, a fifth went to nursing or residential homes and the
2 remainder returned to their own home, sometimes with extensive packages of
3 care from social services and community nursing teams. Post-discharge care
4 involved a large number of external agencies, including Social Services, General
5 Practitioners, community and mental health services, nursing and residential
6 homes and equipment suppliers.

7

8 In contrast to the hospital setting, interactions between community-based
9 professional-practice groups were much less frequent, with limited
10 opportunities for face-to-face interaction and reliance on indirect
11 communication around separate patient-encounters. Correspondingly, patients
12 and families played a more active coordinating role, acting as intermediaries
13 between professional-practice groups to reconcile differences in working
14 practices and perceived failures of communication. To illustrate, social services
15 across both study regions had recently undergone efficiency-led re-organisation
16 involving the installation of a central 'contact centre' to allocate referrals
17 amongst local social work teams, replacing former arrangements for hospital-
18 based social workers. Re-organisation was seen as causing significant failures of
19 communication.

20

21 *'We haven't got social workers in the hospital. [this happened] In the last*
22 *three weeks, four weeks. They refuse to come out and see the patient. We*
23 *then have like six different phone calls in an hour from different social*
24 *workers about patients. So you spend that hour on the phone to different*

1 *social workers and you're answering the same question that you've just*
2 *answered'* (Occupational Therapist)

3

4 Social workers described how the re-organisations meant they had limited
5 knowledge of the patients being discharged beyond generic referral information,
6 making it difficult to assess and plan for post-discharge care. Social workers
7 commonly complained they now lacked direct contact with expert hospital
8 clinicians, often relying on a simple written description of the care provided (on
9 the referral form) without the ability to ask questions about patients'
10 rehabilitation needs.

11

12 *'The disconnect now is pretty massive – [social workers] often have very*
13 *little idea of what is needed when we get to that first appointment. That's*
14 *when we know where to go'* (Social Services Manager)

15

16 *'All I want to know is that the risk is being appropriately managed and if he*
17 *goes home and knocks his thing off his face and dies in his sleep, that we've*
18 *done everything we can to do our best to prevent that from happening. And*
19 *I need a medic to tell me that because I don't know.'* (Social worker)

20

21 Levels of trust between health and social care providers were evidently low, and
22 there was widespread scepticism about the usefulness of information contained
23 within documents that were shared across dispersed groups.

24

1 *'the discharge summary that goes out, patients get a copy of that, but often*
2 *because it's filled in by the junior doctors it's quite a cursory document at*
3 *times and it doesn't necessarily reflect what's happened.'*

4 (Orthogeriatrician)

5

6 *'I sometimes get these letters [holding an example]; often they're next to*
7 *useless. I just have to start again and ask the patient if and when they show*
8 *up' (General Practitioner)*

9

10 Despite multiple referral systems and channels of communication, the
11 coordination of services in the community appeared to rely on patients and
12 families acting as a 'backup' point of coordination. Rather than through planned
13 'involvement' purposefully instigated by professional groups, patients were seen
14 to become increasingly involved in navigating the system when gaps appeared to
15 them.

16 *'Well we should get referrals through the SPOC [single point of contact] and*
17 *then receive these [referral forms] complete. But quite a few times recently*
18 *we just get calls "where are you" kind of thing [from the patients]' (Social*
19 *worker)*

20

21 Outside of hospital, patients and family members understood themselves as
22 needing to be more pro-active in coordinating the work of various groups, and
23 described learning from their experiences of the gaps in inter-agency care. For
24 example, patients and family members described the steps they had taken to

1 organise referrals and follow-up care, shared information between groups and
2 chased incomplete or missing care tasks.

3

4 *'I just got [husband] to phone [re-ablement team] and we said you should*
5 *have been here before 10. We've supposed to have the [community] nurse*
6 *coming out any time to take out the stitches and I'm getting more and*
7 *nervous that they won't come and we'll have to chase them'* (Female
8 patient)

9

10 *'I'm having these injections for the DVT thing and they said I could have a*
11 *nurse come in for that, but I just do it myself.'* (Male patient)

12

13 *'when I took her in, to the physician's assistant and I even know his name*
14 *because I saw his badge. And I said to him, because he said about blood*
15 *pressure or something. I said, 'No, but she's on digoxin for irregular*
16 *heartbeat'.* (Nursing home carer of female patient)

17

18 Over time, patients and carers appeared to gain an increasing knowledge of the
19 health and social care system, and discussed taking on increasing responsibility
20 for orchestrating care, through use of 'professional' language of technology,
21 treatments, roles and responsibilities.

22

23 **Discussion**

24 The findings show how the coordinating role of patients changed as they move
25 through the stages of discharge, from the acute hospital and into community

1 setting. In early post-surgery recovery, a common script amongst ward-based
2 clinical groups helped coordinate the tasks of rehabilitation and care, seemingly
3 underpinned by a shared understanding of the relatively passive and static post-
4 operative patient. Frequent face-to-face interactions within the shared physical
5 space of the hospital ward, together with the boundary infrastructure of the
6 post-surgical pathway combined to support the development of a common object
7 of care, but left little room for patient involvement in decision making. Parsons
8 (1975) made clear that his 'sick role' concept did not necessarily (or mostly)
9 imply that patients become passive objects for professional manipulation, but
10 rather that particular features of context, including the nature of the condition
11 and care setting, may lead patients to play a more or less passive or active role
12 while cooperating with health professionals to aid their recovery. Here, inter-
13 professional work was coordinated through reference to patients (their bodies
14 and health status) *as if* they adhere passively and statically to existing
15 professional categories, with the post-operative patient conforming sufficiently
16 to this to allow coordination to continue. In this respect, the post-operative
17 patient might be regarded as a 'de-activated' boundary object at the centre of a
18 highly prescribed and tightly managed care pathway

19

20 As preparations for hospital discharge progressed, the coordination of
21 professional input became less prescribed, as the individual circumstances
22 affecting longer-term patient recovery were considered in care planning. Care
23 trajectories diversified in preparing for discharge and the central challenge of
24 coordination concerned divisions between the clinical and the psychosocial
25 aspects of care, resulting in greater tension over the appropriate role of the

1 patient. In this context, the patient took on a more ambiguous and contested
2 coordinating role. Certain aspects of the discharge process required patients to
3 more actively contribute their subjective preferences, experiences and intentions
4 to the formation of care plans. During preparation for discharge, we then see the
5 patient as 'activated' boundary subject, defined by a rising (although still
6 contested) expectation amongst the actors involved that patients' subjectivities
7 will contribute to coordination. This co-existed alongside - and within - the
8 standardised bureaucratic processes, seen as essential to maintain the
9 throughput of the hospital department, which required a continuing level of
10 objectification. As such, the patient existed in a dual-state of being
11 simultaneously an object of managed inter-professional coordination, and also a
12 subject of individualised care planning. This duality created tensions for
13 discharge planning, as demands for streamlined care management were often
14 complicated by personal circumstances and, at the same time, the scope for
15 clinicians to address individualised care needs was limited by the need to
16 manage care to prescribed pathways and time-scales.

17

18 Following discharge from hospital, interaction between professional groups
19 became much looser and more dispersed, with gaps in coordination and explicit
20 conflict and disagreement. As noted elsewhere (Levina and Vaast,, 2005), remote
21 communication tools were often insufficient to achieve the level of mutual
22 understanding required for cross-disciplinary working, and coordination
23 between dispersed agencies delivering community-based care was seen as
24 threatening patient safety (Waring et al., 2015). While patients remained a
25 fulcrum around which individual groups organised their services, away from the

1 mutual gaze of the MDT they no longer provided a reliable and shared boundary
2 object. In this context, patients and carers found themselves more autonomously
3 responsibly for navigating elements of the health and social care system, and felt
4 required to actively instigate care activities in light of perceived failings of inter-
5 organisational coordination. In view of this, patients and families could be
6 described as taking up a type of 'boundary spanner' role in which they actively
7 needed to mediate the professional boundaries widely shown to complicate
8 post-discharge care (Glasby 2000). Williams (2002) defines boundary spanners
9 as the key agents or intermediaries that enable effective cross-boundary
10 coordination, involving the use of particular social skills, abilities and personal
11 characteristics. While much literature on boundary spanners assumes high
12 degrees of individual agency, here we see such agency as an extension of the
13 socially conditioned boundary subject, where individual responsible for
14 coordinating care arises from the minimal support from state health and social
15 care agencies. This required patients and families to learn new skills and adopt
16 new practices of coordination, but it also required them to accept themselves as
17 agents of their own care.

18

19 Previous literature has identified the contribution of various boundary objects to
20 the coordination of care across health and social care boundaries (Allen, 2009;
21 Oborn et al, 2013). The shifting boundary role of the patient described here
22 sheds further light on the challenge of professional boundaries, highlighting both
23 the coordinating role played by the objects at the centre of the care process as
24 well as their contested nature. On one hand, when patients act as boundary
25 objects they represent a salient point of common orientation and allowed

1 interpretive flexibility across the professional-practice groups providing care.
2 This contrasted with many of the purposefully designed boundary tools intended
3 to facilitated discharge, which were often limited to particular boundaries and
4 disconnected from work practice. On the other hand, patients did not afford the
5 standardisation expected of other elements of the boundary infrastructure
6 (Timmermans and Areling, 2009), with the heterogeneity of patients remaining a
7 central challenge of organising multi-professional care. Previous literature on
8 boundary objects has avoided casting people as occupying this role. We argue
9 this places artificial limits on the concept, unsupported by the theoretical
10 premises that underpin it, which hold that boundary objects are enacted into
11 being through cross-boundary use (Star 2010), with our research demonstrating
12 the patient can and does routinely act as a boundary object at the centre of the
13 cross boundary coordination under certain conditions. However, while all
14 boundary objects are socially constructed and may be considered to play an
15 active role in the coordination process, patients remain distinct from other
16 boundary objects previously considered due to their potential to move into the
17 role of boundary subject, characterised by a shared expectation that patients
18 subjectivities should contribute to the coordination of their own care.

19

20 In certain respects, this study reflects Mol's (2002; 2008) work in observing the
21 multiplicity of patient bodies, enacted through the technologies and practices of
22 multi-professional care. However, in foregrounding professional boundaries, and
23 including patients' and families' reflections on their care, we highlight the
24 tensions that underpin the multiple formations of patients' as objects *and* as
25 subjects of coordination. New activities to elicit 'choice and voice' offer

1 opportunity for professional and occupational groups with a remit to account for
2 holistic and individualised care needs in their work; in turn, such activities
3 encourage patients to make decisions and express views in order to become an
4 active contributor to the management of their care. Drawing on Foucault's
5 (1991) work, empowering patients to be actively involved in their own care can
6 be seen as a form of 'neoliberal' or 'entrepreneurial' governmentality in the
7 absence of more directive (or disciplinary) professional care. In this sense,
8 clinical groups take on a pastoral role in re-constituting patients' subjectivities
9 and establishing the moral parameters of involved conduct (McGivern et al.
10 2017; Waring and Latif 2017), in such ways that patients (as boundary subjects)
11 take responsibility not only for managing their own care, but by implication for
12 coordinating care services in the absence of effective coordinating technologies
13 to mediate professional boundaries.

14

15 Our findings provide a rejoinder to existing patient involvement literature
16 (O'Hara and Lawton, 2016; Ellins et al., 2012). We suggest that patients are
17 central to the coordination process, but that this role is heterogeneous, not
18 limited to prescribed decision-making processes and may entail a more active
19 coordinating role in repairing or making up for deficiencies in formal
20 organisation (O'Hara et al 2018). Patient involvement and empowerment are not
21 straightforwardly produced, but rather sit more comfortably with professional-
22 practice groups whose knowledge and expertise rests on accounting for the
23 personal and social circumstances of patients and service users, while other
24 groups may be reluctant to engage or resist these tasks. Our study suggests we
25 cannot take for granted a direct correlation between active involvement in the

1 care process and increasingly positive experiences of care. Indeed, our study
2 found instances of patients' reporting positive experiences whilst occupying
3 relatively passive roles as boundary objects and conversely, patients reporting
4 negative experiences of being called upon to express subjective wishes or exhibit
5 agency as the coordination of care.

6

7 Active coordination and decision making clearly involves additional work, and
8 patients and family members were often surprised at this effort and frustrated
9 by the gaps they saw in inter-professional coordination. In other words, we can
10 consider patients and families as intrinsic to the translational work (Allen,
11 2014a) of moving themselves across the health and social care system. This
12 perhaps suggests more consideration needs to be placed on preparing patients
13 for their boundary roles. Writing to propose a vision of the future of health
14 services in 1988, Strauss and Corbin argued we should recognise that it is the ill
15 and their families who do the major work of managing chronic illness and
16 therefore a new relationship between acute care and the patient should be
17 installed which takes this into account. This study suggests we are still trying to
18 find a way to address this call.

19

20 **Conclusion**

21 Patient involvement literature argues that stimulating patients and families
22 involvement in the coordination of health and care systems will lead to
23 improvements in care quality. This study finds patients already making a central
24 contribution to the coordination process, but that the form of this contribution is
25 dependent on wider relations with and between agencies contributing to their

1 care. Active involvement is not an unequivocal 'good' but plays into the
2 professional politics and gaps in coordination within a health and social care
3 system under significant strain. This does not necessarily suggest ambitions to
4 further patients' involvement should be curtailed, but it does indicate that more
5 could be done to understand the implications of involvement activities at the
6 system level. As healthcare systems experience common challenges of stretched
7 resources and growing demand, the expectations placed on citizens when
8 adopting the role of the patient appears a pressing topic for contemporary
9 debate.

10

11

12

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