healthwatch
Dorset

Going Home

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BACKGROUND

A number of people had told us that after they have been a patient in hospital, they faced issues once they were transferred from hospital back to their place of residence, including problems with packages of care (not in place or not what was expected) and lack of information about what to expect post-transfer in terms of self-management. Some of these issues can lead to emergency re-admissions (which is a national, as well as local, concern).
So, we chose people's experiences of transfer of care as one of our areas for investigation in 2018-19.

Work has already been done on gathering patient experiences of the transfer process (from both acute and community settings). Healthwatch Dorset itself contributed to the extensive report by Healthwatch England, and the Adult Inpatient Survey asks a number of questions about patient experiences after leaving hospital.

We decided to build on the foundation of the Adult Inpatient Survey to gain a more in-depth understanding, from the patient/family/carer viewpoints, of what happens after leaving hospital –

- what support, after-care and ongoing care people receive
- what works well and what could be developed and improved to help reduce re-admissions and potentially reduce people requiring further interventions from health and/or social care services.

For example, one of the questions in the Adult Inpatient Survey asks, "Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?" with the option to respond "Yes", "No" or "I don't remember". What the survey cannot tell us is whether patients/families/carers used that information, whether it was accurate or how helpful and effective it was. We can only find out what actually happened, and learn from those experiences, by talking to people after the event.

The benefits of undertaking this work would potentially include:

- a better and more in-depth understanding of the experiences of patients and families after transfer from an acute care setting,
- Identification both of what is working well and also of what could be improved.
- Identification of how well services are working together and what particular areas may need some focused attention to better enable reaching the goals of more care outside hospital and more effective and integrated services in communities.

We approached all three acute hospitals in Dorset to agree to us undertaking at least 60 semi-structured conversations with recently transferred patients (20 from each hospital) and (where appropriate and with consent) their families and/or carers. This would be a random selection of patients, with a view to undertaking further conversations with a more targeted patient group depending on the results of the first cohort of conversations.

It was agreed that we would pilot our approach with The Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust (RBCH) towards the end of 2018. RBCH was agreed as the pilot site due to our methodology requiring input from hospital volunteers and RBCH has a more established volunteer membership and scheme.

METHODOLOGY

PHASE 1

A full Communications rollout was discussed between Healthwatch and RBCH to ensure staff and patients were aware of the project. This included information for staff on screen-savers and through bulletins/newsletters, posters throughout the hospital and information on ward “TV” screens. Posters were displayed for one month before the project began, in order to conform with Trust Information Governance and GDPR.

Information Governance at the Trust were also consulted, and they advised on information storage and retention and other aspects of the project. All three acute Trusts (through their Patient and Public Engagement Leads) were involved in designing the pilot, including the interview questions.

Healthwatch volunteers (with enhanced DBS checks) were recruited to work alongside hospital volunteers to attend wards (over the course of one week) to talk to patients due to be imminently discharged, asking for consent for Healthwatch to contact them 2/3 weeks after discharge. (Note - hospital volunteers were given information and support from Healthwatch before approaching patients). The Trust used the national Adult Inpatient Survey filters to ascertain appropriate wards/directorates to be visited (filtering out patients under 16 yrs., obstetrics/maternity including spontaneous miscarriages, patients admitted for planned terminations, psychiatry patients, day cases and private patients).

Ward staff helped to identify those patients due for imminent discharge. All wards and directorates (within the filter) were visited by volunteers in order to get a sample cohort from across the Trust. The results from the interviews would potentially direct us to the type of cohort that would give us the most useful information e.g. older people may have more needs most discharge than younger people, or elective patients may have less need of post care then emergency patients due to more time to prepare etc. We did not want to “pre-judge” the cohort.

An A5 leaflet giving a brief overview of the project and a consent form were provided for volunteers to discuss with patients. The hospital’s PPE Lead briefed all staff prior to the week volunteers were attending wards and a Healthwatch member of staff was on site at all times when patients were being approached in case of need or in case patients wished to talk about other aspects of their care. Patients were reassured that they could change their minds at any time and would be under no obligation to agree to a conversation/interview when contacted further.

All signed consent forms were handed directly to the Healthwatch member of staff who uploaded them onto a secure system, after which they were destroyed on site.
No hospital staff had access to the patient details, to ensure independence.

PHASE 2

A total of 68 patients gave consent to be contacted. Although initially we had intended to undertake 20 interviews, it was decided to commit to contacting ALL patients who had given consent, in order to gather as much information as possible. Altogether, a total of 37 phone interviews were undertaken by Healthwatch staff 2/3 weeks after discharge (the remaining 31 either declined to be interviewed, were not contactable or were unable to take part for various reasons). Some interviews were conducted with patients and some with family or with carers (with patient consent). Interviews were recorded (again with consent) and then transcribed and anonymised. Recordings were then deleted. Interview questions were developed with input from stakeholders where possible (including the three Trusts, community pharmacy, DCC and a GP Extentivist).

PHASE 3

The interviews were transcribed, summarised and the main “positive” and “negative” issues documented and shared with the Trusts (at this stage not a publicly available document).

Next steps

A review of the pilot will take place with all Trusts and next steps discussed.

Summary of feedback received from patients discharged from the Royal Bournemouth Hospital

(Each line contains feedback from one patient or family. Good on the left, not so good on the right.)

👍	👎
• Contacted by nurse post-discharge.	• Didn't need the equipment he was given.
• Very good information provided about care and aftercare in booklet and information evening event.	• Lack of support/advice/training on use of surgical stocking. Information booklet had no information on surgical stockings. • The lack of training meant an anxious time for the patient and they had to pay for private support. • Had to chase up district nurse for aftercare appointment.
• OT (occupational therapist) visited home pre-admission to check situation and provide necessary equipment/aids. • OT also discussed post-discharge self-management. • Was contacted post-discharge by hospital to check on progress.	• Friends are providing support and aftercare, but hospital did not speak with them.
• Received useful booklet on discharge re info about after-care. • Had pre-admission visit at home by OT from CH assessing post-discharge needs. Equipment/aids sorted out and ready for when she went home.	• Didn't feel she had the opportunity to ask the questions she wanted to. • Didn't feel she had enough information about the operation and what to expect post-discharge in terms of pain and aftercare. • Dressings needed to be changed at local community hospital as no nurses at GP. • Felt she wasn't really treated as an individual, just another job.

• Got a bit alarmed because the physiotherapist called the day after discharge asking for assessment at St Leonard’s hospital. They weren’t expecting this to happen that quickly.	• Changes to parking outside the unit have caused lots of problems. The two spaces for dropping off/picking up are always full of hospital transport vehicles.
• Good booklet with lots of useful information.	
	• No fixed abode. Discharge was delayed a couple of days as hospital needed to find suitable nursing home.
• Even though she had some negative comments, she wanted to reiterate that she couldn’t fault the staff and the care.	• Didn’t get enough information about what to expect post-discharge in terms of pain. • Didn’t feel they had a chance to talk/ask questions. • Was moved 4 times. Not a problem but would have been nice to know why. • Doesn’t know whether hospital will inform her about tests or whether she has to call them. • Had slight issue with pharmacy. She is expert in own care due to various long-term conditions. Felt she wasn’t listened to and because she wasn’t allowed to take a particular medication (because it was not “written up”) that would have solved a flare-up of a condition. She had 2 days of unnecessary pain.
• Staff fantastic and food good.	• Not given enough information on how to manage condition after discharge. Unsure whether to rest or to exercise. • Medication needed change by GP after discharge.
• Staff under obvious pressure, but still had time for him.	
• Was told about independent advocates (due to mental health issues). • Hospital arranged taxi to mental health unit. • Physical and mental health teams worked well together.	• Delayed discharge due to waiting for bed in mental health unit.
• Additional aids/equipment ready at home for discharge	• His wife is his carer - unsure of what she can expect/get as a carer. • Was moved wards at midnight with little explanation.
	• Delayed discharge for medical reasons.

	• Told would need follow up but concerned hasn't heard anything. • No information about what do until follow up - told he would get information at next appointment but not sure when that's happening. Unsure what to do about resuming normal life due to condition and not knowing what's happening next. • Felt overwhelmed at discharge and it would have been good to speak to someone one-to-one. • Wasn't given an emergency number. • Felt he had to fight to get medication some days. • Spent 3 days on AMU - hard to sleep there with night time ward rounds. • Was moved to other area but lack of communication about why and then moved again at 10.30pm. Worried that family wouldn't know where he was and concerned about his things moving with him.
• Had lots of information to come home with (took 2 days to read it all!).	• Wasn't confident about coming home. • Felt staff were so rushed he didn't really feel able to take their time to ask the questions he had. • Staff so busy it sometimes took 15 mins or so to get something asked for.
	• Didn't get much information about aftercare and what to do when home. • Hospital didn't ask about home situation and whether any social care needed. • No contact number given. • Had to stay in A&E 9 hrs before bed on ward was available.
	• As a family they weren't really given much information - its complex because he was in for epilepsy then he went back into hospital, when HWD saw him, he was having chest pains.

	• Lots of problems with medication for the epilepsy - lots of side effects - through pharmacist they are trying to get hold of a particular brand which works for him - the hospital gave him a different brand which made him ill and he went back into hospital.
• Good consultation with patient and family about making decisions to treat the patient at home instead of requiring further hospitalisation. Everything was in place for this to run smoothly.	• Slight delay in discharge due to wait for medication. Was woken at 4.30am to get ready for discharge.
	• Delay in discharge due to waiting for hospital transport home. • Very nervous of using wheelchair and felt that the person pushing her didn't care about her feelings. • Had "Home from Hospital" which was great in providing everything ready for home but is very unsure and worried about when it finishes and what happens next. Lack of information/communication. • Didn't feel she got the information she needed. • Issue with medication and communication between hospital and pharmacy/GP (GP not knowing that her medication had changed).
• Staff in A&E communicated very well. Very different to how it was on the wards.	• Lack of communication about many aspects of care. • Lack of honesty in communications. • No one spoke about aftercare, medication or anything. • No one explained why she was moved to different wards. • Staff so rushed there's no one to talk to. • No contact number given. • Self-funder living on own - had no help organising care needs. • Has care at home (from care agency) but they aren't allowed to enter her home when she is in hospital. This

	means she is worrying about her home all the time she is in hospital (curtains, heating etc.).
	• Not enough information about aftercare and how to manage condition and when to resume normal routines and activities. • Didn’t feel she got the right information at the right time. • Not offered follow-up at Bournemouth – has to go to Salisbury. • GP and district nurses did not know about her discharge – she had to inform them herself. GP did not receive discharge letter. • Different district nurse at each visit and they had to ask patient what was required each time. • Had problems with medication post-discharge. • Food was disgusting.
	• Has some mental health problems and has own social worker. Felt the hospital kept pressurising her into talking to hospital social worker. • Unsure what some of her medication were for.
	• Would have liked more information about what to expect after the operation as he had some problems and ended up back in A&E. If he’d been told about certain things the problems would not have happened.
• Given lots of information about their conditions and aftercare.	• Didn’t feel ready to leave as still felt weak. • Didn’t feel family had enough notice of discharge (discharged at 7.30pm) • Wanted more about “why” issue happened.
• Pre-operation assessment provided lots of information about operation and what to expect post-discharge.	• Not enough toilets on the ward. Many people there for urinary issues and often she had “accidents” due to having to wait for a toilet.
• Had specialist nurse to contact. Had to contact her a few times and it was very useful.	

• Staff were very busy and rushed but always had time for patients.	
• Equipment/aids needed at home were in place for discharge. • Excellent care.	• Delayed discharge due to waiting for medication. • Had useful information about what food to eat but the food they gave her in hospital was on the “don’t eat” list of the information. • Family not offered support as carers.
• Given 64-page booklet with lots of information about everything. • 2-week appointment with rehabilitation nurse gave him opportunity to ask questions about medication.	• Took most of the day to sort medication for discharge. • Didn’t really get drugs explained to him well in hospital. Insisted on explanation before taking new drug. • Had to stay in hospital when no medical reason to - needed another stent - consultant told him to stay because if he left, he would have to go back on the waiting list. So, took up a bed for nothing.
• Good communication between hospital and family about patient care. • Fantastic nursing care.	• Family felt they could have had better information about patient aftercare needs. Didn’t feel they got the right information at the right time. • GP had letter from hospital with follow-up actions needed but these were not carried out, so family had to chase surgery. GP gave appointment for blood test, but family used pharmacy instead because it was quicker. • Family had to find out information about medication themselves through the internet.
• Staff took family situation into account and communicated well with family. • Hospital did make contact post-discharge to check up on medication.	• Not given emergency contact number. • Very anxious about leaving hospital. • Didn’t get enough information about medication (or didn’t understand what was given) and had to get carers involved with hospital and pharmacist to understand what was needed. • Lack of information on what to do/expect when home.
• Staff very informative and family were involved in care planning and discharge.	• No contact number given. • One issue with medication. Hospital didn’t tell the family what medication she had before coming out, so they

• Patient is self-funder, but the hospital gave recommendation about carers.	weren't sure whether to give her the medication when she got home. Family need to know how to follow on.
	• Would have liked more information about his conditions and what to expect post-discharge
	• Lack of communication and involvement of family in all aspects of care and care planning. • Daughter (carer) no idea of support available or what she can expect as a carer. • Carer felt they didn't get enough information about what to expect in terms of the patient's behaviours and how to cope and what to do at home. • Daughter (carer) is dyslexic and nobody took the time to help her understand the information given, especially about medication. • Never got the chance to talk with doctors when mother in hospital – would really have wanted to do so.
• Found it hard to take in information while in hospital but a paramedic who came to see her post-discharge explained things.	• No explanation when scan was cancelled (spent day 'nil by mouth' for nothing). • Staff sometimes "cheesed off" if she needed help with toilet at night.

Our Recommendations

Many, if not all, of the actions we list here are already happening, but they are not happening consistently and in every case. For the benefit of all concerned, what every patient and family can expect should be shared in written form and, in each individual case, each action marked as completed or in process (with an account of when and how it will be completed). This should be talked through and verified with every patient and/or family before discharge, so that there is a record of what has been discussed and what has been agreed.

- **Planning for discharge and aftercare:**
    - As a matter of course, always involve family, friends and/or carers (as appropriate for each patient) in both discharge planning and agreeing what support will be provided, when and by whom, once the patient has returned home. This should be provided in written form to both the patient and to family/friends/carers before discharge, and talked through with them, to ensure that they both understand what it proposes, agree with it and commit to their part in it.
    - If a patient or family member is expected to carry out any procedures themselves after discharge, ensure that they receive training, confirm with them that they have understood what they have to do, and provide them with information about who they can contact if they have questions or problems.

- **Information:**
    - Before giving any information to the patient or family member yourself, first ask them what questions or concerns they themselves have. This will help you tailor the information to the individual, ensuring they have what they need but are not burdened with more than they need.
    - After you have passed on the information you want to, check back with them both whether they have understood the information and whether they have any more questions or concerns.
    - Carry out regular reviews of all information provided to patients and families, in terms of its language, its format and its medium.
    - Do not use jargon and do not make assumptions about what the patient or family members know (e.g. who is responsible for what; how a particular process or system works).
    - Establish a Reading Group of volunteers who will review all information provided to patients and families, looking at it from the patient’s or family’s perspective and assessing it for accessibility.
    - If information that has been given subsequently needs to be changed (e.g. the cancellation or rescheduling of an appointment or procedure), inform the patient and family at the earliest possible opportunity, explain the

  reason for the change, and give them the opportunity to ask questions or express concerns.
- In general, the four major principles when giving information should be:
    - use plain language
    - keep it brief
    - make it relevant to the individual
    - tell people where and how they can get further information or support if they need it

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