Delayed Transfers of Care (DToC) & the Voluntary and Community Sector in Greater Nottingham

Findings and Recommendations

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Building Health Partnerships

IVAR

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This report has been written by Charlotte Pace and Vita Terry from the Institute of Voluntary Action Research. It is based on interviews and desk research carried out by the authors with a group of researchers from the voluntary, community and social enterprise sector (VCSE), Nottinghamshire County Council (NCC Adult Social Care) and the Integrated Health & Care System (ICS).

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Building Health Partnerships (BHP) in Nottingham and Nottinghamshire

1. Background

The national Building Health Partnerships programme is working with the voluntary, community and social enterprise sector (VCSE) and the Nottingham and Nottinghamshire Integrated Care System (ICS) to help create a better picture of **what it will take to reduce the number of patients who end up staying in hospital when other options (in particular going home) would be far better for their health and well-being**.

The focus of this action research project is the Greater Nottingham area, with a specific focus on Nottingham University Hospitals (NUH).

A recent study[1] by Adult Social (2017) care conducted in Nottingham reviewed 24 cases where patients had been discharged from hospital with a social care or joint package and found that 42% could have had a better pathway out of hospital. If better decisions had been made this could have resulted in 21% savings for health and social care. This is an important issue to address, primarily for the health and well-being of the patient but also to create a more effective and efficient health and care system that makes the most of all its assets.

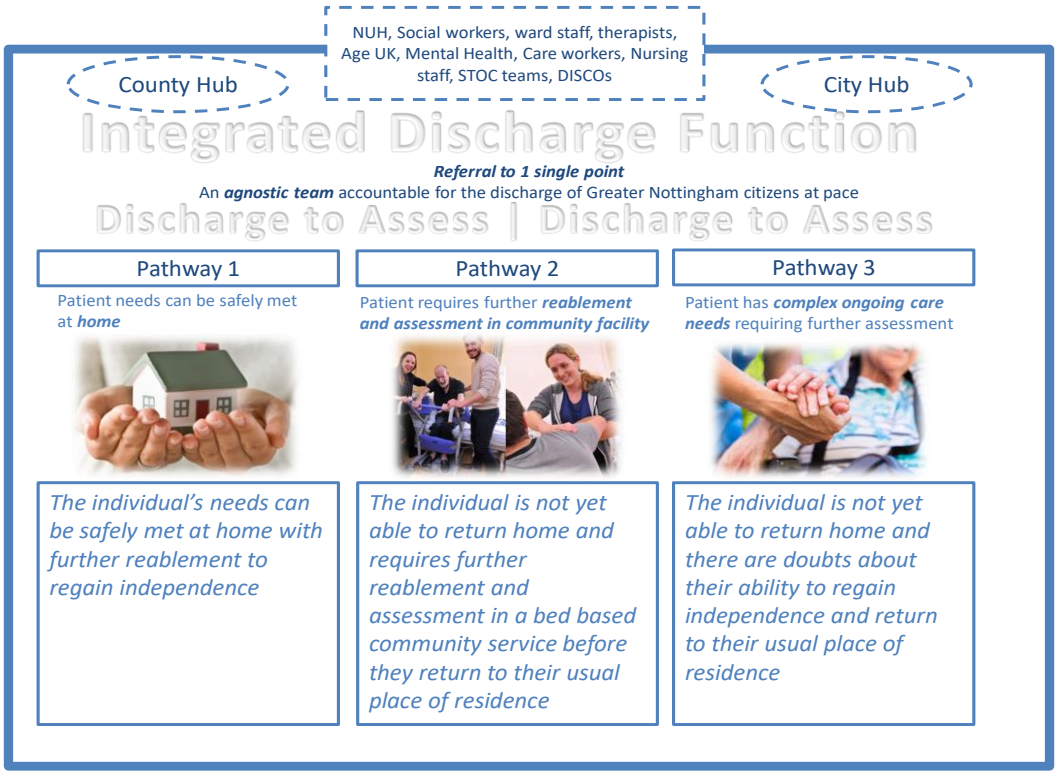
The programme builds on cross sector partner feedback from an event held in November 2018[2] and has undertaken an Action Research Learning process to identify better ways to support patients to leave hospital safely and to live independently.

The research exercise was led by the VCSE sector and involves contributions from colleagues across the sectors. The core partnership group consists of Nottingham Community & Voluntary Service (NCVS), Nottingham University Hospitals, Adult Social Care, the Integrated Care System and Healthwatch Nottingham and Nottinghamshire (HWNN).

This has been a unique opportunity for VCSE organisations to share perspectives on the services and support already being provided in the **Greater Nottingham** community, and to learn from local experiences where it is possible to improve outcomes for patients leaving hospital (and to avoid admissions in the first place).

The diagram below illustrates the hospital pathways for discharge. This research project was focused on **Pathway 1 – 'Patient needs can safely be met at home'.**

[1] This was an internal research report '*Commissioning of hospital discharge* packages' based on a study by the Adult Social Care team conducted in July 2017.
[2] https://www.ivar.org.uk/our-research/building-health-partnerships/



The core group recognised that an important part of this enquiry has been to listen to VCSE experiences of delivering services and support that help people leave hospital to live independently – and to understand what is required for these to be improved in the future.

This was also an opportunity to:

- Hear the voices of a diverse range of VCSE organisations and share learning around delayed transfers of care
- Build better relationships across the VCSE and health and social care to create a long-term partnership legacy
- Input into the development of an action research plan with potential for future investment (e.g. appropriate packages to support patients going home).

Cross sector researchers held a series of conversations with key people in organisations to understand:

- How the VCSE sector can support patients over 75 going home with dementia (who are medically fit for transfer to leave hospital) back into their own home
- If and how existing services could be scaled up and/or expanded to support this group (and potentially others with long-term conditions) to leave hospital earlier.

The resulting recommendations, at the end of this report, will catalyse a partnership and joined-up activity with NUH. They also potentially make the business case for building capacity in the community and shifting investment – and pressure – away from acute services. The exercise has also led to improved knowledge of VCSE work in this area and the development of cross sector relationships. Senior buy-in and investment plans are now required to build the capacity of providers and reduce delayed transfers of care for this patient cohort (and possible others).

2. Methods and participants

2.1) Project aim

- To better understand how the VCSE sector can help in getting dementia patients, who are over 75 and medically fit for transfer, out of hospital and back into their own homes
- To increase opportunities for patients to leave hospital and live independently for longer, with a 'home first' approach that will reduce delayed transfers of care from the acute trust.

2.2) Project objectives

- To develop a framework for an action research approach to support local partnership working that could be applied to other areas of health and well-being
- To promote co-production as a way of working on complex health and social care issues
- To identify at least one action or project to scale up/roll out and monitor for impact on patient outcomes and experience.

2.3) Research design

The research was led and conducted by the VCSE sector and took place over different stages.

First stage: Scoping phase

To gain an initial understanding of the organisations and groups that may be able to support DToC in the Greater Nottingham area, NCVS undertook a scoping exercise. Its aim was to identify a long list of voluntary sector organisations that could potentially provide help in getting patients (medically fit for transfer) out of hospital and back into their own homes. Different data sets were drawn on, including:

- NCVS database
- Self Help UK directory of self-help groups in Nottingham and Nottinghamshire https://www.selfhelp.org.uk/directory
- Alzheimer's Society Find Support near you https://www.alzheimers.org.uk/find-support-near-you
- AskLiON directory https://www.asklion.co.uk/kb5/nottingham/directory/home.page
- Notts Help Yourself directory https://www.nottshelpyourself.org.uk/kb5/nottinghamshire/directory/home.page

From this exercise, NCVS was able to draw up a long list of 57 VCSE organisations to be contacted for interviewing.

IVAR provided a researcher briefing session at NCVS in May 2019. Researchers were provided with a toolkit (co-produced) to conduct the research. This included an information sheet, topic guide, template to write up interview notes, and checklists for the process (please refer to Research Pack Tool Kit that will be made public in November 2019 on the Building Health Partnerships website).

In addition to the work taking place directly with organisations, in May 2019 Healthwatch Nottingham & Nottinghamshire were commissioned by the Building Health Partnership Programme to interview family members of people living with dementia, in order to understand how the voluntary and community sector can support delayed transfers of care.

As part of this project, HWNN interviewed five family members at Nottingham University Hospital and conducted follow-up with two of them after their relative had been discharged (sadly we were unable to complete post-discharge interviews with family members of three patients as they passed away).

Second stage: Briefing and conducting interviews

From the long list drawn up, NCVS agreed a system to allocate interviews to be conducted by cross sector members from the BHP core group and other volunteers (social care, NHS, VCSE, etc). VCSE organisations were selected for interview if they were well positioned within the geographical location; provided varying types of support and services for individuals over 75 living with dementia and met the sample criteria outlined in section 2.4.

In total, 14 face to face and telephone semi-structured interviews were conducted, using a co-designed topic guide, to better understand the VCSE contribution and value both in this project and in general. Researchers produced interview notes using the write-up template in the tool pack which was used for the analytical process.

Third stage: Analysis of the interviews

IVAR collated the 14 write-ups and conducted the analytical process. Analysis was undertaken by using key themes from the topic guides. The report (first draft) was shared with the BHP core group in June 2019.

Fourth stage: Developing the action plan

At the BHP core group meeting in July 2019, the key findings and learning from the action research were used to inform the development of an action research plan. The purpose of the plan was to identify a course of action to assess the research findings and consider the future potential for partnership opportunities – including reflecting on any gaps in current service provision.

Dissemination and outputs

- Long list of 57 VCSE organisations
- 14 interview write-ups with VCSE organisations
- Excel sheet of the interview findings
- Report outlining research and headline findings
- Development of an action research plan

2.4) Participant organisation sample

Researchers were allocated organisations from the long list of 57 voluntary and community organisations and were responsible for setting up and conducting interviews. The organisations were selected on the following criteria:

- They had expertise – or provided services – in the field of health, social care and well-being and already were, or could adapt to, supporting people to leave hospital/live independently with dementia.
- The organisation did not need to be working with the patient before they left hospital: the focus was on those that could support people with getting home/staying at home and avoiding readmission.

- The organisation could be providing support to family and friends as well.
- Organisations were asked about what their current and potential offer.
- Specific protected characteristics organisations (BME/LGBT) would be included if they provided, or could provide, the support.

The organisations operated across the four Clinical Commissioning Group (CCG) areas in Greater Nottinghamshire, including Nottingham City CCG, Nottingham North West CCG, Nottingham North & East CCG and Rushcliffe CCG.

In total, 14 interviews were conducted with VCSE organisations; a list of the participants is outlined in appendix one.

3. Summary of services and support in the community

3.1) What is out there to support people over 75 leaving hospital with dementia?

Ahead of the research, the cross-sector core group – specifically Nottingham University Hospitals and the Adult Social Care and Public Health Transformation Team – identified the following areas of support that are commonly cited by patients and their carers as help that could make a difference. The overarching themes were housing, benefits, and low-level needs, e.g. befriending, gardening, cleaning and shopping.

Leaving hospital (including A & E):

- Reassurance, a friendly face – helps with the discharge planning
- Support with shopping on discharge, or support to access support from their local community

Settling in on return home:

- Accompany/meet and greet at patient's home to help them settle in, particularly if they have no family close by
- Welfare checks to prevent readmissions for patients who have declined social care support on discharge
- Physical and emotional support for patients who have to be discharged to housing aid, e.g. those requiring a daily welfare check, accessing food banks, etc.
- Support Packages of Care for low-level needs – for example, where there is no capacity for a QDS (four times daily) care package, social care can support the personal care aspects and the voluntary sector support others, e.g. meal prep, medication prompts, welfare checks, basic shopping
- Support discharge of patient a day earlier than start of Package of Care (POC), e.g. with an afternoon/evening call if POC can start the next morning
- Support to avoid social isolation for the patient

Well-being support:

- Carer stress/strain support to provide support for the carer – pressure on carers can often be a barrier to discharge where crisis has resulted in a hospital admission
- Provide carer events to support and reduce strain

The research found that all of the above support – and much more besides – was available in the Greater Nottingham area, being provided by the VCSE sector in the community.

From the conversations, demand for services and support from voluntary sector experience was described as (not in order):

- Elderly with dementia
- Enduring health needs, e.g. immobility, long-term mental ill health or learning disability – require support to live independently
- Loneliness and isolation (befrienders/no family network or someone unpaid)
- Mental ill health
- Recent bereavement
- Supporting carers
- Support with recreational activity
- A desire to take part in the community
- Practical – transport, EOL
- Housing
- Older people suffering with social isolation and associated issues such as depression and anxiety (sometimes mistaken for dementia)

Some examples of services/support/activities:

The Community Cares Club takes people out into the community (especially those who are otherwise housebound), can cook meals at home or deliver lunches (usually at independent living complexes). They also do cleaning, liaison with health and social care to support hospital discharge and are advocates for service users – communicate with health and social care/complete forms on behalf of a service user.

A self-help group for Caribbean elders meets every Tuesday for a chat and bit of a lunch. They also do handicrafts, have lunch, outings, and even recently went to Scotland for the weekend.

Nottinghamshire Mind provide counselling and dementia support services, a memory support service, specialised mental health groups as well as training for professionals and organisations.

Gedling Homes provide an independent living assistance service to support independent living, e.g. adaption at home, cleaners, hot food, etc. The Lifeline service is a community alarm for people living at their own home or in supported housing. They also facilitate other community activities such as employment, job clubs and there is a partnership with Gedling Council for a social prescribing service as well.

Other examples include programmes to prevent people going into hospital in the first place; volunteer transport; befriending; counselling; disabled facilities grants; advocacy, and more nuanced support like footcare and a Grumpy Old Men group. Creative Paths CIC provide a range of creative and learning activities for people with dementia – for example, story and memory projects to express a life story. Through these, the organisation is also raising awareness of older people.

A running theme of the exercise was helping people to remain living independently in their homes. This is the core purpose of The Helpful Bureau, who provided a long list of their services and support. They also have a community transport scheme, with volunteer drivers with a wheelchair-accessible vehicle funded by Broxtowe Borough Council.

Three conversations took place with housing providers revealing that there is a wide range of supported housing and community care on offer from each one. In one case – Nottingham Community Housing Association (NCHA) – housing and care each account for an equal portion of the overall business. Tuntum Housing Association already provide bungalows to accommodate clients aged over 75 but have no specific service for, or linked to, discharge pathways at present. However, work is under way to see how they can support someone being discharged from hospital who may require an interim care package before returning home.

There is significant reference to navigator, community connector or similar roles that are either in place or are considered to be the best way to link things up.

'A health and housing co-ordinator is currently in their second year. They work with NUH & Highbury hospital in Bulwell, and in Ruddington too.'
(Council Officer)

'It would be great to have one person to pass information to, to build a relationship and be more coordinated – currently it happens in a random way.'
(Coordinator, self-help group)

'There are Carers Champions at Doctor surgeries – and those that provide a community liaison function (or Link Worker) in particular hospitals – it needs to be more coordinated.'
(Coordinator, self-help group)

In some cases, these sorts of roles *were* in place but are no longer funded. They are mostly framed as an 'ask' for the future. These valuable roles could ensure VCSE resources are used well, for the right people, at the right time – in turn saving time and money. They are also a way to bring hospital and VCSE support closer together.

Support for carers – seen as being inextricably linked to patient support and well-being – is offered as a core service in Hucknall and, where possible, by other organisations in this sample too. Social prescribing also featured where it was happening in that location. Gedling Borough Council and Gedling Housing fund a social prescribing group (SPRING) and give grants to community organisations and set up volunteers as community navigators. The over 75s and lonely or isolated can access this programme. However, there is currently no direct referral route from the hospital. The value of the non-clinical approach was unanimously supported, and the need to have that support facilitated seen as equally important.

'Recognise a person's social well-being – all the elements that they need in their lives to generate healthy and positive outcomes. This includes making resources more inclusive (not putting everything online).'
(Project manager, small voluntary sector organisation)

The above is just a flavour of what is already happening in the Greater Nottingham area but is not a full appraisal of all that is, or could be, available in the community; it is a sample that has been able to shine a light on just a fraction of what exists.

A set of development ideas at the end of this report picks up the ideas and suggestions made by participants in this research project.

3.2) Referrals – how do they work?

These were described in a range of ways, informal and formal. The VCSE referrals are faster than those with/from statutory agencies, as the latter are often means-tested and people have to meet a set of criteria defined by the local authority (if they provide funding). Different services have their own referral system and – where the criteria are set by the commissioners – this is often slow and, from a provider perspective, also costly.

'Often have the situation where there are empty properties and in a mental health crisis – referrals take so long and are complicated for those with high support needs.'
(Senior Manager, housing association)

The British Red Cross shared the example of the Winter Pressures Discharge Service, whereby they are informed of a service user who is fit for discharge so that the service can take them home on the same day. This supports service users who struggle to get into passenger transport as well. All service users receive a follow-up call once they are home to check they are safe and well. The Red Cross act as a 'bridging service' for a one-week period whilst the GP is able to establish a longer-term service.

For Tuntum accommodation and sheltered housing, there is a 50/50 mix of self-referrals/word of mouth referrals and those from other organisations (specifically the YMCA). At Nottinghamshire Mind people can self-refer – or have an agency referral – online, or they can telephone the office. Phone referrals are particularly helpful for those unable to use the internet proficiently.

'We don't have any kind of formal or informal relationships of discharge with hospital.'
(Senior Leader, housing association)

There is evidence of strong relationships between the hospital and the Gedling Homes Lifeline team. This initiative enables individuals to return to the community more quickly because it means they can call on help when they are back at home. It is clear that some inroads have been made to see if there is a way of working together to make a better referral at NUH. However, challenges arise because there does not yet appear to be a way of aligning the different services.

'For people in hospital there is not a route for them to access our housing. Other than the discharge team they would have to make enquiries to the local authority to get priority banding and then that would only work if a property became available in that period of critical time.'
(Senior Leader, housing association)

3.3) Exclusion from services

Overall, there was a general narrative from the respondents that their services were open, inclusive and accessible to a wide range of individuals, spurred by the underlying ethos that 'no one gets turned away'. The exception to the rule was when service delivery was associated with statutory requirements, which could mean certain individuals did not fit the criteria for eligibility. Access guidelines may also be a barrier, but one that can usually be overcome.

'To access sheltered housing individuals should be over 50 and in receipt of disability welfare, however the council will decide who these people are.'
(Senior Leader, housing association)

Although the voluntary sector does not intend to exclude anyone from accessing its services, other barriers that stem from a lack of resources and capacity can be problematic. For example, these can result in:

- Difficulty accessing transport
- Difficulty accessing funding
- Difficulty communicating and coordinating between the voluntary sector and the health and social care system due to lack of networking, forums, meetings, etc.

In the case of Nottinghamshire Mind, there had, in previous years, been potential for service users and health staff at Kings Mill hospital to be involved in the early stages of hospital admission, and hence in critical future planning. However, there is now much less scope for such participation due to the removal of funding.

4. What is the value of including the voluntary sector to deliver support to people over 75 leaving hospital with dementia?

The respondents said that they felt the health and care system was 'not aware of what we [the voluntary sector] do, and the services we have available.' They believed this meant the voluntary sector was not always invited to be at 'the table' to discuss certain issues. In addition, services that could potentially avoid a detrimental impact on a patient's overall experience were not being utilised by the heath and care system. All the respondents felt that the voluntary sector, in supporting patients, provided an 'added value' that was essential and should therefore be included in the early planning stages of hospital care. This included:

- **Professional services** – as demonstrated in section one, these are being delivered by trained staff.

- **Embedded within the community** – by providing services to individuals within the community, the voluntary sector develops relationships, trust, and extensive knowledge about the local community. This is also advantageous because the VCSE have extensive reach into the community through the services they provide.

- **Signposting and networks** – the respondents described the breadth and variety of signposting that was taking place, which demonstrated the VCSE knowledge about the local community and other services being provided. By building networks and

relationships, VCSE organisations are well placed to signpost to other relevant services and understand which service fills which gap in provision.

'it's like putting pieces of a jigsaw together, networking is key to this'.
(Coordinator, self-help group)

- **'Going the extra mile'** is how one respondent described VCSE values, passion and commitment to providing a solution in supporting the community and caring for people. One example of key individuals going above and beyond their job roles was the Head of Independent Living at Gedling Homes, who was crucial to setting up the Social Prescribing programme in Gedling, targeted at issues around isolation. https://www.gedling.gov.uk/resident/community/socialprescribing/

- **Flexibility** – the VCSE are described as being less constrained than the public sector and, therefore, they have the ability to be more flexible and responsive in provision of support to the community.

- **'More input from people who can make changes happen'** – from being well embedded within the community, and with strong values and commitment, the VCSE are able to engage positively with communities and therefore understand the support needed to help people live in own their home.

- **Cost saving** – it was commented that 'the public sector don't realise how much we are saving (by using volunteers and having a wider reach)'. The wider system also benefits from the VCSE ability to take a more preventative approach and refrain patients from going into hospital in the first place, thereby reducing the length of time spent in hospital.

The conversations repeatedly highlighted a need to take a longer-term view – both of care for people leaving hospital (so not just the 'settling back in at home' aspect) and in supporting the sustainability of the VCSE sector overall.

5. What is needed to develop voluntary sector support around DToC?

There was a common theme around the things that get in the way of building partnerships with statutory agencies to better support DToC. The health system can be viewed as complex to navigate, with service delivery pressures meaning that new solutions from outside seldom penetrate the traditional way of doing things. It feels quite chaotic despite the goodwill that is often evident (and there is evidence of positive relationships that do exist, too). Questions from participants included: Are there simple pathways we can plug into? Is there a way of avoiding so much competition and pitting organisations against each other, instead of playing to each other's strengths?

'Keeps me awake – the lack of appropriate funding to deliver safe services – it's a deficit funding model, we need full cost recovery to make this work.'
(Senior Manager, housing association)

All those participating in this research were either already providing services or support for the patient cohort aged over 75 with dementia – or could do, with adaptions. Nottinghamshire Mind, for example, run a specific Dementia Service. However, as with most of the other organisations, their reach is much broader, so there is potential for many other patients to benefit from the support available in the community. What organisations were able to provide was always dependent on resources; however, not one stated that they would not be able to provide any support at all.

'Not connected yet to over 75's with dementia but could be yes!'
(Manager, voluntary sector organisation)

It is notable that funding has been withdrawn from several schemes. These include Tuntum Housing, where the respite unit closed in the summer of 2017. Rushcliffe CVS was commissioned by the CCG to run six patient participation groups in Rushcliffe but there is no longer funding for that. The Helpful Bureau had benefited from a Health Trainer promoting a non-clinical well-being approach; funding for this post was cut.

Overall it was felt that the NHS could find ways to communicate more with all parties and sectors and view the voluntary sector as an equal partner in the care process. Language was also considered important, as was a common understanding of the difference between care homes and supported housing – really quite different types of provision.

'More conversations need to happen and more joined up thinking and working. We talk about it but it doesn't happen in reality.'
(Coordinator, voluntary sector organisation)

'When I sit in a health and housing meeting I hear a lot of stuff that sounds phenomenally complicated on what seems to be going on but not making any difference. I have been clear with my colleagues that I want to support them but I can't keep going to meetings where I don't understand.'
(Chief Officer, voluntary sector organisation)

The research process itself started building connections between social care and providers, in particular by making organisations aware of others not previously on their radar. A cross sector approach appears to be key in working together to find solutions to support patients to leave hospital when they are ready.

6. Healthwatch Nottingham and Nottinghamshire findings from patient and carer interviews

In May 2019, Healthwatch Nottingham and Nottinghamshire (HWWN) were commissioned by the Building Health Partnership Programme to interview family members of people living with dementia[3]. The aim was to understand how the voluntary and community sector can support delayed transfers of care.

As part of this project, HWNN interviewed five family members at Nottingham University Hospital and conducted follow-up with two of them after their relative had been discharged (sadly we

[3] Healthwatch Nottingham and Nottinghamshire (2019) *NUH Tackling Delayed Transfers of Care.* September 2019. See appendix two for full report.

were unable to complete post-discharge interviews with family members of three patients as they passed away).

The findings from the interviews showed that none of the family members had received a 'Home First' leaflet or had a planned discharge date. Neither were they thinking about the needs of their relative or their needs following discharge. Instead they were preoccupied with the present, i.e. whether their relative would be discharged, or finding a suitable care home. Two relatives spoke of, and were very grateful for, adaptations that had been provided by the Red Cross, and a third spoke of advice their relative had received from Age Concern in the past. Three relatives felt reluctant to engage with more services, describing how dealing with their relative's dementia had made them withdrawn, suspicious of others or unable to engage with others. The only needs that were mentioned concerned washing and dressing, which relatives had arranged home care to assist with.

Relatives themselves had not considered the support that the VCSE could offer them, including whether the VCSE could provide support if their relative was taken into nursing care. One person described how more information about what is available would be useful – for example, attendance allowance and how to apply for it.

These findings illustrate that, unless relatives are made aware of what support the VCSE can provide, it is difficult for them to identify their needs. It was also apparent that these relatives put the patient first and that they themselves may be in need of support or advice from the VCSE in their role as a carer. Providing more support to people living with dementia – and their carers – before they become critically ill is an area that the VCSE could assist with, as long as volunteers are consistent and adequately trained.

Recommendations: NHS & VCSE sector jointly developing support around Delayed Transfers of Care at Nottingham University Hospitals

Project outcomes:

Short term:

- To better understand voluntary sector support available for the client group within the community and to inform ICS on capacity
- The BHP DToC programme findings feed into the **Community Centred Approaches Workstream** to inform emerging developments such as social prescribing
- The BHP DToC programme becomes part of the **Urgent Care Winter Communications and Engagement Plan** and **ICS Urgent Care Workstream**
- Use the BHP programme to explore better ways to communicate the principle of 'Home First' and ensure patients and their carers receive the Home First leaflet
- To gain a better understanding from people who care for people living with dementia of the associated needs

Medium term:

- To improve the experiences of people with low-level dementia and their families/carers in the discharge process, by reviewing their current support and how the voluntary sector could provide support that would meet their needs
- To start to utilise effectively – and feed into development of – social prescribing and community connectivity services across Greater Nottingham
- Increase utilisation of services available with a 'home first' approach, improving patient and carer outcomes and experience and reducing delayed transfers of care from the acute trust

Long term:

- To raise awareness (e.g. through an information leaflet) of what the voluntary and community sector can offer to support DToC, initially for those leaving hospital with dementia and their carers
- Share learning, for an improved understanding across the whole health and social care system, by illustrating the value of including the sector in early planning stages to create a more enabling form of support for patients and their carers on discharge (using this research as a benchmark)

- To build a sustainable relationship between the VCSE and the ICS – developing an approach where engagement is core and all system partners are clear about how it leads to improved outcomes of care for patients and improving system flow

NHS	VCSE	Action/outcome	Lead
1. 'Helping you to get Home First' - how can volunteering support DToC? And connect with local VCSE organisations at the same time?			
Identify Hospital Volunteer Coordinator for NUH Volunteering Programme and review how volunteers are involved with DToC now Key features now: • Support with meals • Visiting/befriending • Carer support	Identify capacity of NCVS volunteer pool and expertise – what is current reach into NUH?	• Link NCVS/Rushcliffe CVS/other with coordinator of NUH volunteering programme and NUH charity • Meet to discuss opportunities/needs/mutual support – how can volunteering support DToC? • Explore the ways to build capacity across Greater Nottingham – including with the Patient and Public Involvement team • Connect to Hospital communications to look at ways volunteering is promoted • Provide volunteer training on DToC patient needs (this report included) • **Pre-Winter Marketplace** (event to be held at hospital) – a key action agreed to initiate connections (as above) and build awareness of voluntary and community sector support around DToC	Hospital Volunteer Coordinator, NCVS, Notts County Council
Outcome/s: • A more effective volunteer offer to DToC, bridging support in, and on discharge from, hospital and the first few days at home/or longer according to need (including connecting with relevant VCSE organisation); this will reduce unnecessary longer stays in hospital • Develop volunteer skills and expand hospital volunteer ward role to support patients and their carers to go home in a timely way • Redirect resource from Acute Trust into volunteer support and development and community support, to help people and their carers to go home			

NHS	VCSE	Action/outcome	Lead
2. Planning for discharge (and preventing hospital admission): Pathway 1 – Home First			
Review the role of the VCSE in Pathway 1	Meet with Integrated Discharge Team, and raise awareness of VCSE partners; review existing discharge pathways and where VCSE fits	• Integrate VCSE offer and support into discharge planning – helping to ensure patients leave hospital in a timelier way (ref this report) • Design referral process into VCSE organisations, in partnership • Consider opportunities for workplace shadowing (hospital and VCSE workforce) and training sessions led by VCSE at hospital • Explore whether VCSE have a role in supporting patients and their carers who are discharged to nursing homes • Capacity building of VCSE – link with social prescribing initiative via Community Centred Approaches Workstream • Identify hospital space for VCSE information (leaflets/info etc) on B floor (with NHS Charity); include a desk for volunteers. (A new leaflet may be required that encompasses all the VCSE support available – it would be good to get feedback from carers before this is published.) • Look at ways to engage the VCSE when designing services, understanding the skills they bring • **Pre-Winter Marketplace** (event to be held at hospital) – a key action agreed to initiate connections (as above) and build awareness of VCSE support around DToC	NCVS, Adult Social Care, Hospital Discharge Coordinators
Outcome/s: • Good cohesive pathways out of hospital and better outcomes for people and their carers at home • Faster and more effective discharge • A hospital hub (base or space) for the VCSE at NUH – a presence in hospital • Raised visibility of VCSE organisations in Greater Notts – to NUH			

NHS	VCSE	Action/outcome	Lead
3. Housing solutions to support patients to leave hospital when they are ready and medically fit for transfer			

Make link to Housing & Health team to connect housing providers to NUH directly	The Housing Associations and Care and Support providers forum (a joint project supported by the National Housing Federation and the Arden & Gem CSU) are keen to engage and pilot/develop solutions	• Identify existing relevant activity within ICS and key leads from health and VCSE
		• Share/table the DToC report at relevant health & housing meetings/with key groups
		• Utilise results to design a set of proposed solutions to be 'tested' that might include:
		  ○ Identify suitable accommodation/beds for DToC needs
		  ○ Create a new system for communicating between the hospital and housing providers (e.g. complete weekly returns on beds occupied/available – location/postcode would be key)
		  ○ Design packages of care for patients without suitable accommodation on leaving hospital
		• Pre-Winter Marketplace event
			Nottingham University Hospitals

Outcome/s: • Reduce number of patients with dementia in hospital when they do not need to be, resulting in fewer hospital bed days, etc. • A faster discharge pathway (Pathway 1 definitely, others?) for those with dementia (could include homeless and other vulnerable groups too, including those with no recourse to public funds)			
NHS	**VCSE**	**Action/outcome**	**Lead**
4. **Community Transport**			

Home First to liaise with VCSE via lead contact to identify community transport available	Provide summary of VCSE community transport offer to support safe and affordable transport to enable independence	• Understand what is available already – by postcode • To support hospital transport, additional funding would assist with service development, marketing, and passenger and volunteer recruitment • Transport providers to attend/share information at Pre-Winter Marketplace	Nottingham, Rushcliffe and Broxtowe CVS Broxtowe and NUH
Outcome/s: • Reduce use of commercial patient transport to reduce NHS costs • 'Map' of accessible and affordable community transport offer across NUH with costs • Increased independence to support people's health and well-being			

Appendix one: Participant organisation sample list

- **British Red Cross**: https://www.redcross.org.uk
- **Carers in Hucknall**
- **Community Cares Club**: https://www.communitycaresclub.org/
- **Creative Paths CIC**: http://www.creativepaths.org.uk/
- **Gedling Homes**: https://www.gedlinghomes.co.uk/
- **Gedling Seniors / Gedling District Council**: http://www.gedling.gov.uk/
- **The Helpful Bureau**: http://www.thehelpfulbureau.org.uk/
- **Marcus Garvey Day Centre:** https://www.carehome.co.uk/day_care_centre.cfm/id/65432192218
- **Nottingham Community House Association**: https://www.ncha.org.uk
- **Nottingham Mind**: https://www.mind.org.uk/
- **POhWER**: https://www.pohwer.net/
- **Rushcliffe Community and Voluntary Service**: http://rushcliffecvs.org.uk/
- **Self-help group for African Caribbean Elders**: https://www.selfhelp.org.uk/directory/entry/broxtowe-african-caribbean-elders
- **TunTum Housing Association**: https://www.tuntum.co.uk/

healthwatch
Nottingham & Nottinghamshire

Tackling delayed transfers of care from Nottingham University Hospital Report

September 2019

Commissioned by

Building Health Partnerships

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Executive Summary

In May 2019 Healthwatch Nottingham and Nottinghamshire (HWWN) were commissioned by the Building Health Partnership Programme to interview family members of people living with dementia in order to understand how the voluntary and community sector can support delayed transfers of care.

As part of this project HWNN interviewed five family members at Nottingham University Hospital and two after their relative had been discharged (sadly we were unable to complete post discharge interviews with family members of three patients as they passed away).

The findings from the interviews showed that none of the family members had received a 'Home First' leaflet or had a planned discharge date. None of the family members were thinking about the needs of their relative or their needs following discharge. Instead they were preoccupied with the present, i.e. whether their relative would be discharged or finding a suitable care home.

Two relatives spoke of and were very grateful for adaptations that had been provided by the Red Cross and a third spoke of advice their relative had received from Age Concern in the past. Three relatives felt reluctant to engage with more services describing how their relative's dementia had made them withdrawn, suspicious of others or unable to engage with others. The only needs that were mentioned were with washing and dressing which relatives had arranged home care to assist with.

Relatives themselves had not considered the support that the VCS could provide them with or whether the VCS could provide support if their relative was taken into nursing care. One person described how more information about what is available would be useful for example attendance allowance and how to apply for it.

These findings illustrate that unless relatives are made aware of what support the VCS can provide it is difficult for them to identify their needs. It was also apparent that these relatives put the patient first and that they themselves may be in need of support or advice from VCS in their role as a carer. Providing more support to people living with dementia and their carers before they become critically ill is an area that the VCS could assist with as long as volunteers are consistent and adequately trained.

Introduction

Healthwatch Nottingham and Nottinghamshire were commissioned by the Building Health Partnership Programme to carry out 6 interviews of family members of people over 75 who are living with dementia. The aim of this project was to understand how the voluntary and community sector (VCS) can support medically fit patients living with dementia (and their carers) to leave hospital and return home. This could include re-enablement, regaining independence, social prescribing and community connectivity service models across the ICS. Three family members (one for each patient) were interviewed twice, once while patients were in hospital and again following discharge from hospital.

The interviews form an extension to a larger study (by HWNN) of people over 75 years of age being discharged from Nottingham University Hospitals (NUH), focusing on the specific needs of a small sample of people living with dementia. Nottinghamshire County Council's Home First Response Service is seen as key to accessing community and voluntary sector support.

Background

The national Building Health Partnerships programme is working with the VCS and Nottingham and Nottinghamshire Integrated Care System (ICS) to help build a better understanding of what it will take to reduce the number of patients who end up staying in hospital when they are medically fit for discharge and when other options would be far better for their health and well-being. The programme's Core Group identified that better use of community resources and less risk-averse discharge planning for people living with dementia could improve independence and reduce costs to health and social care. This is based on national research into people living with dementia admitted to hospital. It is estimated that approximately 25% of beds in hospitals are occupied by people living with dementia. Their length of stay is often longer than for people without dementia and there can also be delays in supporting them to leave hospital.
https://www.dementiastatistics.org/statistics/hospitals/

Limitations

There were several limitations with this project, principally, the logistics of organising interviews before and after discharge with carers of people living with dementia. In practice three patients died in or after leaving hospital and new participants had to be found which led to delays in completion of the project. Dementia *A state of the nation report on dementia care and support in England* 2013 found people with dementia also stay in hospital for longer, are more likely to be re-admitted and more likely to die than patients admitted for the same reason.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf

Our approach

HWNN approached a Care of Older People lead at NUH ward B47 at the end of March 2019. This lead person identified patients who fitted the following criteria:

- In-patient of NUH
- Over 75 years old
- Living with Dementia
- Resident in the Greater Nottingham area. i.e. City, Broxtowe, Gedling, Rushcliffe
- Going home
- Has a family member available for 2 interviews

HWNN worked in conjunction with the Building Health Partnership programme to develop a set of questions. These included:

- Have any voluntary organisations such as The Red Cross/Age UK etc. been involved in planning your relative's discharge?
- Do you know of any voluntary organisations that will support your relative getting home?
- Do you know if any voluntary organisations have been asked to make arrangements for the care of your relative once home?

Our findings

Initially it took a number of weeks to meet with the NUH lead, identify people for interview and to gain consent from them to participate in this project. The schedule of interviews is detailed below:

Interviewee	Arrival date in hospital	Date of interview	Discharge date from hospital	Date of second interview
1	17/05/19	23/05/19	24/05/19	28/05/19
2	19/05/19	29/05/19	Deceased	N/A
3	02/04/19	29/05/19	Deceased	N/A
4	03/06/19	10/06/19	Deceased	N/A
5	05/06/19	11/06/19	20/06/19	10/07/19

When it became apparent that the second and third patient were not going to be discharged within the timeframe of this project (one had a temperature and infection another because they were under a DoLS order) HWNN agreed to approach two more patients. Sadly one of these patients died before the second interview took place.

The findings described in this report therefore are based on a first and second interview with two relatives and first interviews in hospital with three others.

All five relatives described not receiving the Home First Discharge letter, they therefore had no questions about it. Relatives of all five patients did not have a

planned discharge date. The reasons given were, *'I haven't been given a date. My sister was phoned by Social Services today to say that the hospital contacted them and told them that she's been getting an iron infusion today and then she'll be fit for discharge. I've just had a conversation with the doctor and they're also talking about wanting to do a scan before she's discharged, so I don't know how long we have to wait for that,'* and *'Dad's had a setback over this weekend, he's had a temperature and an infection'.* This illustrates that planned discharged dates may not be apparent as patients conditions change and that therefore it is inappropriate to involve VCS in the planning of discharge, getting home and managing at home.

It became clear from the interviews that participants were not thinking about their relative's needs or support that could be provided by the VCS while their relative is in hospital. One relative described how they didn't know if their relative would be discharged, *'today was the first day that it was spoke about that he would be discharged'* therefore making it redundant to consider support needs on returning home. Responses from other relatives were as follows, *'We're waiting to hear about a care package', 'my sister and I are now looking for a Care home/Nursing home' , 'I think they are sorting it out to do something – packages'* and, *'the mission has been to find a nursing home with duel aspect. That's the mission at the moment.'* In each of these cases relatives were dealing with short term urgent and immediate priorities. Until urgent concerns are addressed it is unlikely consideration would be given to other needs such as getting to appointments, shopping etc.

Two people described not having thought about contacting the VCS, one because, *'they haven't decided if he has to go into residential care'* and another described how, *'we don't know if there'll be enough funding for both of them to be in a home.'* One relative had, *'got Red Cross nurses in place at home',* a second described not having contacted the Red Cross but were planning to as, *'that's where we are getting our equipment from.'* In this case they had not contacted them themselves but had had assistance from the Parkinson's nurse who was getting equipment through the Red Cross. In both of these cases relatives described being provided, walking aids, a bed, wheel chair and commode. A third relative talked about how, *'I think my Dad's had advice on some things from Age Concern, they gave him numbers for a hairdresser for her, and he has certainly used Age Concern for advice.'*

Relatives described reluctance from family members to engage with others. One said how an, *'Alzheimer's social worker from our local house centre was visiting Mum and Dad'* before being admitted and how they had offered them carers, however the parents had refused help because, *'they didn't want strangers in the house and felt that they could cope themselves together.'* Similar sentiments were echoed by other relatives, *'Mum is very unwilling to engage with other people at the moment. She will only see family and that's been the case for the last two years'* and, *'my Dad doesn't talk now, it's hard to get any conversation out of him, he's been like that a while now with his dementia.'* These experiences

illustrate the challenge that the NHS, social care system and the VCS face in supporting people living with dementia, *'who in later stages may be less able to recognise people'* and, *'if they don't recognise people, they may feel like they are surrounded by strangers and get distressed.'* (Alzheimer's Society website). Bearing this in mind the VCS will need to ensure staff and volunteers are adequately trained in dealing with people living with dementia in order to reduce the stress to them and their relatives/carers. In addition ensuring continuity has been found to help people living with dementia, e.g. continuity of staff, sticking to a daily routine etc. Therefore if the VCS is to support people going home with dementia, then staff, volunteers and funding will need to be long term, consistent and permanent.

Another finding was that relatives of people living with dementia had not thought about the support they might need or could access for themselves from the VCS. *'As long as he's cared for, if he's alright, I'm alright'* and *'I don't have much of a social life, I had to give up a job, which I loved,'* and *'I've been caring for him for years now and I've had no help because I've managed'* and, *'if I can take a career break, I will, if not I'll hand my notice in'* and, *'at the moment Dad keeps saying he wants to die, I could do with somebody maybe like the Alzheimer's Society or carers to say, 'This is par for the course.'* These examples illustrate that carers are not aware of the support the VCS could provide and so may require signposting as well as assistance in contacting organisations for support and advice.

Experiences from two relatives showed that when a patient is going into residential care there is an expectation that, *'the care home will provide everything'*. There was no concept in these instances that the VCS could provide additional support during visits to the care home.

Two people described the care they felt their relative needed was, *'probably with his toiletries, meaning to have a bath and shower and toilets'* and *'help with his washing and dressing in the mornings.'* In both instances they were looking to social services or a care agency to meet these needs. There was no consideration that perhaps these could be met by the VCS.

We talked to one relative who was interviewed after her husband was discharged and had returned home. In this case Red Cross nurses had been pre-arranged to provide short term care. However Social Services put care in place for the day of discharge so Red Cross care was cancelled. This example illustrates the flexibility that the VCS requires as care needs change. The second relative we spoke to after discharge described how her husband had been moved to a rest home. In this case she felt there was no need for any additional support for her husband or herself from the VCS.

In another case a relative described how, *'it's hard to know until we get home and see how he is because from before he came in to where he is now is a real big difference.'* This presents an issue for both the relative and the VCS in determining what a patient's needs may be while they are still ill in hospital.

Lastly one relative described how, *'I think there are times where more information would have been useful. It took me a while to cotton on to all the attendance allowance.'* This is one example where the VCS could have a role in supporting relatives of family members living with dementia.

Conclusions

Relatives do not know until they've got over the initial crisis/emergency stage what their needs are. They also do not know what their home needs are until they have returned home. It is not uncommon for patients on the Dementia ward to stay a long time therefore more time needs to be allocated to data collection in order to interview relatives after the patient has been discharged. There is a high chance that patients living with dementia may die when in hospital or very shortly after returning home so is important that the VCS and volunteers are aware of this and able to appropriate support or signpost carers at this time if required.

Recommendations

- Ensure volunteers are adequately trained in dealing with people living with dementia and that consistent volunteers are provided
- Develop and make available an information leaflet that describes the support the VCS can provide to people living with dementia and their carers
- Provide more support to people living with dementia and their carers before they become critically ill

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