Healthwatch Norfolk 3-year engagement project on social care services for the over-65s in Norfolk

Year One summary report

Introduction

This three-year engagement project was commissioned by Norfolk County Council's Adult Social Care department to ensure that the voices of older people are heard in the planning and delivery of social care services in the county. It also seeks to identify areas where people using services encounter preventable problems, and to find ways to assist people to find help earlier, before their needs intensify.

The project is set against the backdrop of a globally aging population, which presents significant challenges related to care provision. In the UK and Norfolk, the proportion of older people is substantial and projected to increase further. As demand for social care rises, social care departments face significant constraints, emphasizing the urgency of delivering services for people in a way that is both efficient and responsive to felt needs.

This executive summary reports on the findings and recommendations from year one of the project (you can find the full report here: www.healthwatchnorfolk.co.uk/reports/over-65-adult-social-care-year-one). In year one, we sought to investigate three broad areas of current and anticipated high demand for adult social care services for older people in Norfolk:

- **Older people's voice, choice, and rights:** Understanding how well older people are listened to and their views are responded to by social care services.
- **Social care's role in hospital discharge:** Understanding people's experiences across their whole 'journey' related to hospital admission, from reasons for admission, up to their exit from health and social care into a sustainable living arrangement in the community.
- **Social care support for people with a dementia diagnosis:** Exploring the challenges faced by individuals with dementia and their Carers after a

dementia diagnosis, and any gaps in health and social care services in this area that social care might help to fill.

The primary goal of the project's first year was to gain a wide-ranging understanding of older people's experiences in these three areas in order to inform recommendations for improvement.

We gathered people’s views in three main ways. Firstly, we conducted in-depth interviews with 20 people for each theme of the project (60 in total), asking them about the main research questions of the project, and giving them the chance to raise any other issues that they were facing. Secondly, we used these results to construct a survey questionnaire investigating people’s experiences in the project’s three focus areas. This was completed by 270 people across Norfolk. Thirdly, in the areas of listening and hospital discharge, we also interviewed 30 health and social care professionals for their views on how services listen to older people, and on integrated working in hospital discharge.

Respondents to our interviews and survey were not randomly sampled across the population and do not wholly match the demographics of the population. The number of survey responses we received (270) also mean that the sample would not produce statistically significant findings. There were 223,900 people aged over 65 in Norfolk in 2021 (2021 census figures, Norfolk Insight), and tens of thousands of these receive social care support from the local authority.

Nevertheless, the research from year one of the project yielded a broad range of different experiences and helped us to identify some clear areas for future engagement and policy focus.

Older people’s voice, choice and rights

Initial contact with social care

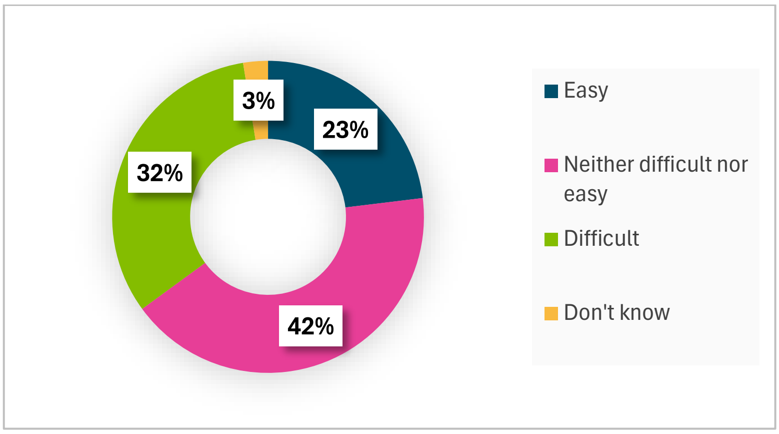

Figure 1: Q4. How easy was it to get through to the service you wanted to speak to?

The first point of contact with social care services for many is the main customer service phone line, staffed by the Social Care Community Engagement team (SCCE). Most people in the survey said it was either “Easy” or “Neither difficult nor easy” to get through to the right service on this line (65 per cent or 76 people out of 117 answering this question). Around one third of people said that they had found it difficult to get through. When people did get through, most people said that they were either well or adequately understood (80 per cent or 92 people). People who were happy with their experience told us that they were confident that they had been listened to, were treated with empathy, and had been able to find information easily.

In the in-depth interviews a few important themes arose about things people struggled with. Some people mentioned that there was a steep learning curve when first encountering social care, for those who had never used services before. People mentioned having trouble navigating the large number of different statutory and voluntary-sector organisations offering help, not understanding some of the language professionals use, and being unsure of what help social care could offer them, and so not knowing what to ask for.

In the survey, 61 people also told us about the impact of having to wait longer than they would have wanted for a response after first contact with social services. The most common impacts mentioned were the worry and stress of waiting (12 people), the impact of not having needs met for a period of time (11 people), the difficulty of providing care for a loved one while waiting (7 people) and the workload of having to chase up a response (6 people).

Care Act Assessments and reviews

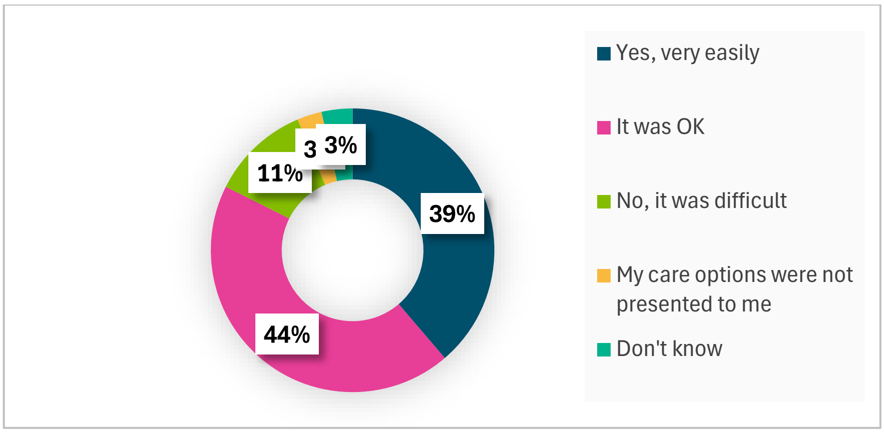

Figure 2: Q10. Were your care options presented to you in a way that you could understand easily?

Most people we spoke to were happy with how their Care Act Assessment had gone, with three-quarters (or 106 people) in the survey telling us that all of the people that they wanted involved in the assessment (such as a Carer, relatives or friends) had been included. 83 per cent of people (or 117 people) who answered the question told us that their care options were presented in a way that they could understand. On the other hand, one fifth of respondents (or 26 people) told us that not all of the people they wanted included, were included, and 14 per cent of respondents (or 20 people) told us that it was either difficult to understand their care options, or the options were not presented to them. A concern that ten people noted in the in-depth interviews was that they felt they were "signed off" too early and would have appreciated check-ins from professionals to see if their care package was working well. The perceived difficulty of initiating a new referral when problems arose was a barrier to getting needed care adjustments.

Experiences with domiciliary care

Sixty-two people told us how well they had been listened to by domiciliary care services. 36 people (or 56 per cent) said that they were listened to well or very well, 15 people (or 24 per cent) said that they were listened adequately well. The remaining 11 people (or 18 per cent) said that they were listened to poorly or very poorly. People who were happy with these services mentioned care staff who listened and responded well, established good rapport with the person they were supporting and responded quickly to requests.

Those who were unhappy with the support they received mentioned the following issues:

- **Lack of Capacity:** Difficulty finding care agencies, particularly in certain areas of the county, and limited flexibility in care provision.
- **Inexperienced Staff:** Concerns about the skills and experience of some care staff, particularly in meal preparation and understanding complex needs.
- **Timing and Length of Visits:** Problems with carers arriving at inconvenient times or providing shorter visits than allocated, impacting the quality of care.
- **Lack of Continuity:** Frequent changes in care staff due to high staff turnover, making it difficult to build relationships and trust.

Professionals' Perspectives

We also interviewed professionals in the voluntary sector and district councils, who are often contacting social services on behalf of people receiving support or advising them about these contacts. These interviews revealed a mixed picture. Most professionals praised the dedication of social care staff to the people they support, but they also identified areas for improvement:

- **Accessibility:** The need to simplify processes, avoid jargon, and ensure information is easily understandable for older people.
- **Communication and Collaboration:** Challenges in communication and collaboration between NCC and some voluntary sector organizations, suggesting a need for improved partnerships.
- **Capacity Issues:** Professionals acknowledged the impact of limited capacity in the care market on service provision and decision-making.

The role of social care in hospital discharge

This section of the report focuses on the critical role of social care in facilitating timely and effective hospital discharges for older people. It highlights the challenges and complexities of this process, particularly in the context of the 'discharge to assess' model and offers insights into the experiences of both patients and professionals.

There are four discharge pathways under the discharge to assess model. Around 50 per cent of in-patients nationally are discharged from hospital on pathway 0, meaning that they return home with no (or minimal) help from services. Around 45 per cent of inpatients are discharged on pathway 1, and require support to return home, usually reablement support, commissioned by social care. Around four per cent of inpatients are discharged on pathway 2, meaning that they move to a community bed-based NHS service for rehabilitation. Around one per cent are discharged on pathway 3 to a new residential or nursing home setting for long-term care.

The NHS is the lead partner in discharging patients from hospital, and acute hospitals identify which discharge ‘pathway’ each person should follow. Where hospital staff judge that a person has additional care and support needs, they will complete a Transfer of Care form which is sent to a ‘Home First hub’ outside the hospital, where a team of health and social care professionals decide what support the person should be offered. Conversations that patients have about post-discharge care therefore mostly happen with hospital staff. Where appropriate, patients may have a Care Act Assessment after discharge, to determine what support they might need to meet their ongoing needs, and these conversations happen with social care staff.

Hospital admission and prevention

In the survey, 124 people told us that they had been admitted to hospital in the past 18 months. Most of these people (68 per cent, or 72 people) did not think that their admission could have been prevented. Of those who thought their admission was preventable, 18 people (just over half) said that falls prevention advice, equipment or home adaptations could have helped. Extensive work on falls prevention is already underway at NCC.

Discharge communications about social care assistance

The report highlights that there are still challenges in communicating effectively with patients and Carers about how they will leave hospital, and with what support. A significant proportion of patients and Carers reported not being involved in decision-making or informed about their post-discharge care arrangements. This varied depending on what (if any) care the person was due to receive. As table 1 below shows, 49 per cent of all respondents (or 45 people) said that they were asked where they wanted to be discharged to, and with what help. However, this figure includes people who were due to go home on pathway 0, without any support. The proportion was higher for people receiving social care after hospital (54 per cent or 28 people).

Care received after discharge	Yes	No	Don't know/don't remember	No. of respondents
All respondents	49%	33%	18%	93
All people receiving social care	54%	25%	21%	52
Reablement	60%	20%	20%	25
Nursing home*/care home	33%	33%	33%	15
None	36%	36%	27%	22

Table 1: Q16.1 While you were in hospital did anyone ask where you wanted to be discharged to and with what help?

*Some of the nursing home placements may have been funded by continuing health care.

46 per cent of all respondents (or 37 people) said that their Carers were not asked what their preferences were for discharge, though again this was lower for those leaving hospital with social care assistance (37 per cent or 17 people). 48 per cent of all respondents (or 58 people) said that they were not given information in good time about the care they would get after leaving hospital (compared to 39 per cent of those receiving social care after hospital, or 25 people).

This suggests that improvements could be made to communications with patients while they are in hospital about their care options, both to give them the chance to state their preferences, and to receive information in good time for discharge. Better communications could reduce uncertainty and anxiety for individuals transitioning from hospital to home or other care settings.

The report also reveals a gender disparity, with women reporting significantly more negative experiences with discharge communications than men. Similar disparities have been found in other areas of the UK, with women reporting more negative experiences around discharge communications than men in all relevant questions in the 2023 CQC national in-patient survey. Nevertheless, this finding suggests a need for further investigation into the causes of this disparity in Norfolk, and the implementation of measures to ensure equitable communication and involvement for all patients.

Care Act Assessments at home

The 'discharge to assess' model involves assessing patients' care needs in their homes or community settings after discharge, rather than in the hospital, and we sought to understand people's experience of these assessments. Most respondents were satisfied with these assessments, with 25 people (around three quarters of those who answered this question) saying that all of the people they wanted included in the assessment were involved, and 27 people (or four fifths) saying that they could understand the care options that were presented to them. Some people in the in-depth interviews told us that they were unhappy because they were told in hospital (by ward staff) that their post-discharge care would be free for six weeks, but this is not always the case.

Care received after discharge

Despite the problems reported with communications around what care they would receive after discharge, most people answering the survey reported being happy with the care they received, which mostly included reablement support, care homes and domiciliary care. Most respondents agreed that their care met their needs (67 per cent or 69 people), took account of their wishes (63 per cent or 61 people), and looked after them in a caring and compassionate way (66 per cent or 65 people). The ability of care to promote independence was less positively rated, with 53 per cent (or 52 people) saying that it had done so, and 34 per cent (or 33 people) saying that it had not.

The feedback we received in the 20 in-depth interviews on this theme concentrated mostly on the reablement support provided by Norfolk First Support (NFS). Almost all the people who mentioned this service said that they were happy with it. They mentioned that care staff arrived promptly after discharge, were compassionate and helpful, and were good at promoting people's independence.

Professionals' views on discharge and integrated working

Interviews with professionals revealed a generally positive view of the 'discharge to assess' model, with most believing it had improved integrated working between health and social care. However, challenges remained, including:

- Differing risk appetites: Variations in risk tolerance between health and social care professionals could lead to disagreements and delays in discharge decisions.

- Capacity constraints: Limited capacity in the care provider market often hindered positive risk-taking and timely discharges.
- Transfer of care form: Inaccurate or incomplete completion of this crucial document could increase the risk of "failed discharges" and readmissions.

Experiences after a dementia diagnosis

In this part of the project, we were interested in aspects of people's general experience of services in Norfolk, whether they be health or social care services, to try to determine what gaps there are in services and how adult social care could help to support people better. Therefore, many of the problems that people mentioned were not directly related to social care services, but to broader issues in the health and social care system in Norfolk.

Thirty of the people we carried out in-depth interviews with had dementia, and we heard about a range of experiences of diagnosis. Most people had been diagnosed at an NSFT (Norfolk and Suffolk Foundation Trust) clinic or hospital. People's experience of diagnosis was mixed, with five people having to push for a diagnosis, with services, usually GPs, seeming reluctant to refer people on for a diagnosis. Such delays can lead to prolonged periods of uncertainty and anxiety for people.

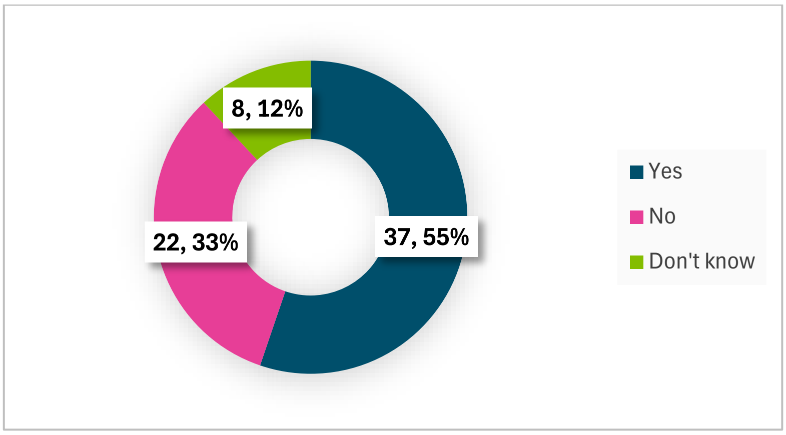

Figure 31: Q23. When you received a diagnosis, did you get support to learn more about the condition?

In the survey, 71 people told us that they had dementia, or were caring for someone with dementia. We asked people whether they had been supported to learn more about their condition after their diagnosis. Just over half of people (37 people) said that they had received information, but a third (22 people) had not. In the in-depth interviews, people reported having received varying amounts of information upon diagnosis. Around a quarter of the interviewees reported being happy with the amount of information that they received, and those who were happy had often received face-to-face guidance from a professional, with those having to interpret information by themselves being less happy. Some interviewees reported receiving no information at all, and Carers, in particular, expressed a desire for more information and training on coping with the challenges of dementia.

Planning for the future

Almost half of survey respondents (32 people) indicated they had not received any assistance in planning for the future after diagnosis. People told us that to plan for the future, they would like more information on the costs of care and who would pay (34 people), the progression of the condition (32 people), and available care options (25 people). Some interviewees also spoke of their desire for proactive support, rather than always having to reach out to services themselves.

Care provision

Most respondents to the survey (47 people, or 80 per cent) felt that the care provided in homes or through domiciliary services was either ‘well suited’ or ‘OK’ for people with dementia, there were calls for more activities and stimulation, as well as increased staffing levels. Carers reported instances where care providers lacked the capacity to manage challenging behaviours, leading to negative impacts on the person's well-being. This highlights the need for specialized training and support for care providers working with this complex population.

Carer’s experiences

Finally, the project also asked Carers of older people with support needs about their experiences of social care services.

Carer's assessments and support

The report examines Carers' access to and experiences with Carer's Assessments, which are designed to identify their support needs and offer relevant services. While around a third of survey respondents (34 people) had received an assessment, around another third (36 people) desired one but had not yet had it, suggesting a gap in access and awareness. Among those who wanted an assessment, reasons given included being unaware of the service, not being offered one, or being on a waiting list. It may also have been that some of these people were not eligible for the assessment.

The survey also explored the types of support Carers had received. It found that 42 per cent of respondents (55 people) had not received any support. Among those who did receive support, the most common forms of help they received were information on support groups or dementia cafes, and respite care. Most respondents found the help that they did receive to be either helpful or OK (26 people or 65 per cent), and people told us that Carers Matter Norfolk had helped them to access useful services, whilst being helpful and empathetic.

Carer breakdown and service gaps

In the in-depth interviews, 13 out of 33 Carers reported feeling overwhelmed and unable to cope with their caring responsibilities. The emotional and physical toll of caregiving, coupled with perceived gaps in service provision, contributed to feelings of stress and exhaustion. The report emphasizes the importance of addressing Carers' needs to prevent burnout and ensure the sustainability of their care.

Respondents to the survey also highlighted the challenges Carers face in managing behaviours that may challenge others. 68 per cent (48 people) told us that they had not received enough support to manage such behaviour, and desired assistance in the form of respite care, care home placements, mental health support, and more timely domiciliary care.

Maintaining relationships and connections to the local community

We asked Carers whether they, and the person they look after, were able to maintain relationships, and links to their local community. 61 per cent of respondents (71 people) told us that they had lost many or almost all of their relationships since developing a social care need. In the in-depth interviews people also told us about problems with socialising. These results suggest that this is an area of great need for older people with care needs in Norfolk.

Recommendations

The Year One project report makes a number of recommendations based on the findings above, which are divided into recommendations that can inform ongoing social care strategies now, engagement and research actions that the project itself will take up in the remaining two years, and longer-term goals for Adult Social Care. The focus below is on actionable short-term recommendations, and includes responses from the Adult Social Care department.

Listening and information

Recommendations

- Information on the social care 'offer' is already available online, yet some older people we spoke to told us that they did not know how to access it and were not always confident accessing online information. New ways of providing older people with information on the adult social care ‘offer’ should be considered, including hard copy materials. Information could be printed in the Your Norfolk magazine, which is distributed to over 400,000 households in Norfolk. Information could also be published in Parish newsletters.
- Newcomers to the social care sector who find it confusing could gain considerable confidence with a short guidance session from a knowledgeable professional. Age UK Norfolk and the Norfolk Community Advice Network both provide telephone advice services, and signposting people to these services when they first develop a social care need could reduce confusion considerably. Such signposting is already happening, but could be increased in settings such as:
    - GP surgeries after someone develops a new health condition or frailty.
    - Acute and community hospitals when older people are admitted.

Response from Adult Social Care

We will:

- Identify what information could be provided in hard copy, recognising that we need to ensure it doesn’t become out of date.
- Make better use of existing hard copy publications to share information.

- Review the information and signposting that is available in GP surgeries and raise this will colleagues in health organisations to see how further information could be provided at key times by health professionals.

Hospital discharge

Recommendations

As detailed above, a significant proportion of patients reported not being asked about their discharge preferences and not being given information in good time about their discharge destination. To begin to remedy this we would recommend that:

- When staff are filling in a transfer of care form or making a referral for patients who will need social care support after discharge, all patients and Carers should be explicitly consulted about their discharge preferences and see that their preference has been written down.
- When staff judge that a patient will not need support after discharge, they should check this decision with patients and Carers and ask about their preferences.

Information for patients in hospital about how social care after discharge will be paid for should be provided in a range of formats. This could include links to existing online information, as well as leaflets or information on tablets for those patients and Carers who do not have smartphones.

Response from Adult Social Care

We will:

- Target Year 2 research to better understand available information and best practice to meet people's needs.
- Liaise with partner organisations as part of ongoing hospital discharge process improvement to share the findings of this report and recommendations and in particular focus on information available to patients in hospital about social care choices.

Support after a dementia diagnosis

Recommendations

The North Norfolk Dementia working group has recently started taking actions which address two of the most prominent findings from Year 1 about dementia services, and we recommend that these are rolled out to other areas of the county. These are that:

- More learning support should be given to people upon diagnosis, and more help to guide people through their options, including on social care and who will pay for it. Information resources have been developed in north Norfolk showing people the process they will go through with services before and after diagnosis, and what support is available to them.
- More check-ins from professionals should be considered and a mechanism for adult social care to be in contact with people earlier in their journey. These are due to be carried out by Protect Now with all people in north Norfolk with a dementia flag on their records, and the Dementia Support Service are contacting everyone awaiting a memory assessment with NSFT.

In addition, measures could be taken in the short-term to reduce the social isolation of some people with dementia. Some of the feedback we received suggests that services providing some dementia peer-support groups were recently recommissioned, putting some local groups under threat of closure. ASSD should verify whether existing groups have been replaced by the new providers and explore options to replace them if they have not been.

Response from Adult Social Care

We will:

- Share the findings of this report with all ICS organisations reviewing dementia care in Norfolk.

Carers

Recommendations

- The feedback that we received suggests that Carers Matter Norfolk's services are invaluable to many older people, but could be promoted to more people, with around one third of respondents saying that they would like a Carer's assessment but had not received one. We recommend that NCC investigates where the service is being promoted, and whether it could be promoted more widely, especially in settings such as GP surgeries and hospital wards, where people may discover for the first time that they have a social care need.
- Carers Matter Norfolk should consider checking in with people after a year, rather than signing them off, where someone is suffering from a chronic or progressive condition.

Response from Adult Social Care

We will:

- Review how carers assessments are referred and opportunities to increase the number of people accessing this.
- Share the findings of this report with commissioners who are in the process of reviewing the existing contract for carers support.