



# Nursing People at Home

The issues, the stories, the actions

## **The Queen's Nursing Institute**

The Queen's Nursing Institute is a registered charity dedicated to improving the nursing care of people in their own homes.

We trained district nurses until the 1960s, in a model that was copied across the world. This model of care was instrumental in developing a comprehensive, highly-skilled service in the UK that meets the needs of millions of people every year.

Today we improve nursing in the home by:

- ✚ Developing Queen's Nurses who are committed to high standards of care in the community, helping them to make improvements in practice and to act as leaders and role models to others
- ✚ Influencing policies in England, Wales and Northern Ireland that affect healthcare in the home and the quality of community nursing services
- ✚ Funding projects led by community nurses that improve care for their patients

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## Foreword

Earlier this year I was asked by the Queen's Nursing Institute to support their campaign - Right Nurse, Right Skills - which I happily accepted.

I did so because, as a former nurse, I know how comforting it is for patients to know that a trained and qualified practitioner will visit when they're ill at home. I find it very worrying that trained nurses are getting thin on the ground, and that they are being replaced by less experienced nurses or health care assistants. This report is all about the patient journey, highlighting their experiences of nursing care at home, and it shows just how important the right nurse can be.

Being looked after is a high quality experience for many people. Patients speak of their nurses so proudly – skilled to cope in a crisis, able to answer questions and willing to go the extra mile. These stories were wonderful to read and reaffirmed my belief that nurses make an invaluable impact on the health and wellbeing of those for whom they care.

However, this report also shows that good care is not universal, and patients are sometimes being put at risk. I was particularly struck by the daily struggles faced by some of these patients, carers and family members. For some it was the inability of their nurse to deliver effective treatment; for others it was dealing with nurses who were rushed and disinterested; for even more it was feeling a lack of compassion and empathy from those who provided care; and for a few patients, it was a nightmare from start to finish. These stories are shocking and upsetting. But, reassuringly, this report shows that, when they have the right skills, the home nursing workforce makes a real difference to patients' lives.

I believe, as this report says, that the home is a truly special place. I call on everyone who reads this report to support the actions it calls for, to ensure that patients receive quality care in the most vulnerable place - their own homes. We are all potential patients, and we all deserve the best possible nursing care, from the 'right nurse with the right skills'.



Julie Walters CBE, award-winning actress and former nurse



“I believe, as this report says, that the **home is a truly special place**. We are all potential patients, and we all deserve the best possible nursing care, from the right nurse with the right skills.”



## Executive Summary

Today, home is the place where many people receive health care, and is much preferred to being in hospital. Being cared for at home places people in a vulnerable situation – due to their frailty, ill health or loss of mobility. This unique setting brings with it inherent risks for patients, nurses and service managers.



### **Right Nurse, Right Skills**

The need for skilled home nursing is rising at a faster rate than ever. To meet this growing demand, community services have been developing new ways of working. The consequence has been the continuing loss of nursing skills in the community.

In response, the QNI launched a campaign last October - 'Right Nurse, Right Skills'. The campaign calls for a properly skilled and trained home nursing workforce, so that patients receive the care that they need. Since we launched the campaign, we have received hundreds of stories from the public, with many describing the impact of decreasing skills on the quality of care.

This report builds on these stories and starts to detail a picture of what matters to people in their experience of their nurses and nursing care. The findings are based on feedback and figures collected through a range of activities including an open-access survey and face-to-face interviews. This was not a research project - we simply wanted to provide the public with opportunities to tell us about their experiences. However, we believe these findings provide useful pointers about what matters to people when they need nursing at home.

### **Report findings**

The public greatly values home nursing, with community nurses seen as delivering a vital service. For the majority the experience was positive – just over 70% of survey respondents rated their most recent experience of home nursing as either 'excellent, very good or good'. For some though the experience was far from satisfactory, with many stories of poor care.

The awareness of patients, carers and family members about the different nurses who come to visit is mixed. Fewer than half (43%) knew whether the person who provided care was a registered nurse.

Nursing skills important to patients include: 'can assess unexpected situations and take appropriate action' (69%); 'coordinates other people and service to help with my care'(60%); and 'keeps me informed, answers questions and offers advice about my treatment' (57%).

Attitudes of nurses important to patients include: 'caring, kind and compassionate' (73%); 'say they do something, and actually follow through and do it' (58%); and 'not rushed, takes time with me' (48%).

## Skills Matter: Competence, Confidence, Caring

Patients and their families recognise and value the expertise of community nurses who are:

**Competent** – up to the task

- ✦ Having good knowledge of a patient's illness, treatments and support systems
- ✦ Interventions, treatments and procedures are performed properly
- ✦ Having the ability to co-ordinate care services and manage on-going care

**Confident** – in a unique environment

- ✦ Poise; they speak with authority and certainty
- ✦ Trust; information and advice is delivered with honesty
- ✦ Character; proud and professional

**Caring** – for me as a person

- ✦ Take their time to understand the person
- ✦ Show compassion for the situation (both patient and carer)
- ✦ Go the extra mile for their patients

All too often patients witness nurses who:

- ✦ Lack knowledge about conditions and treatments
- ✦ Display poor practices
- ✦ Have difficulties with communication
- ✦ Are not reassuring and lack professional confidence
- ✦ Are rushed to complete the 'task'
- ✦ Are disinterested in the patient and their job
- ✦ Do not listen
- ✦ Show little compassion
- ✦ Focus on performing the task – only

## Recommendations

The QNI will:

- ✦ Work with patient and carer groups to develop a range of information resources for patients, carers and family members
- ✦ Launch a national awareness campaign to raise the profile of nurses working in the home
- ✦ Encourage hundreds more nurses to become a Queen's Nurse – committed to high standards in community nursing
- ✦ Create a micro-site on 'Nursing Skills in the Community' aimed at helping employers and clinical commissioning groups



Commissioners should:

- ✚ Require providers to have in place a comprehensive training and development framework for their workforce and on-going patient involvement in the development and monitoring of the service
- ✚ Set standards for community competencies to be held by all team leaders or people in key posts, as part of the appropriate contract for community services with service providers
- ✚ Increase the number of nurses with specific training for the community working outside hospitals year-on-year

Organisations that employ community nurses should:

- ✚ Provide specific community training for all nurse team leaders so that they can ensure patients receive safe and high quality care in the home
- ✚ Ensure all nurses receive skills training to match patient's needs – regular skills audits should be used to identify needs
- ✚ Invest in understanding the patient experience so that they are aware of poor practice and can benchmark performance with the aim of driving up quality
- ✚ Have a programme of support for all nurses new to the community their first six months
- ✚ Include information on the community qualifications of team leaders and key post-holders in their information available to the public

Nurses and nursing teams should:

- ✚ Carry out regular audits of their skills to ensure they match patient needs
- ✚ Carry out appraisals to respond to issues promptly and support good care
- ✚ Ensure nurses new to the community are adequately supported
- ✚ Aim to increase awareness amongst the public of the team and their role and responsibilities to help the patient know who is coming to visit
- ✚ Consider becoming Queen's Nurses, as part of their aspiration to be competent, confident and caring

Patients and families should:

- ✚ Use the 'Being at Home Checklist' – Queen's Nurses' tips about being a patient at home
- ✚ Feel able to ask for the care they need and to question their community nurse
- ✚ Take opportunities to give feedback, praising good care and alerting to poor care



**Why home is special**



A person's home is their castle. Whether it's a council flat, a sprawling farm or a suburban semi, for most of us, home represents a place of comfort, security and tranquillity – a haven from the hustle and bustle of the world outside. For many, home is also the place where they receive health care, and is much preferred to being in hospital.



The care a patient receives at home is varied depending on their individual needs. It might involve hands-on treatment, teaching, assessment, support, tests or the administration of medicines. It might be needed for long periods of time, even over many months or years. Alternatively, some people require short periods of care and some need only a single visit. For many people, it is the community nursing team that cares for them at the end of their lives.

### **Special for Patients**

Whatever their circumstances, being cared for at home places people in a particularly vulnerable situation. People that receive health care at home are:

- ✚ Generally housebound due to their frailty, ill health or loss of mobility - they may need support due to a temporary change in health status, memory changes, or because of a lack of confidence in looking after themselves
- ✚ Reliant on others for help with their care and support needs, which is delivered behind closed doors
- ✚ Limited in their ability to compare their care with others' experience, and so to challenge and question decisions
- ✚ Often isolated and left alone for much of the time, and have to decide for themselves when and who to call for help or ask a question

### **Special for Nurses**

This unique setting demands a nurse workforce with specialist knowledge and skills. The work of the home care nurse is demanding, with the application of clinical interventions – both varied and complex - taking place in a non-clinical environment.

They must be adept at communicating - displaying empathy towards the patient but at the same time reassuring them with a confident manner. It requires the nurse to earn trust by building relationships quickly, and to be able to pass on to the patient the skills to cope at home.

And it also demands a high level of responsibility and risk management - assessing complex needs, coordinating a wide range of services, working closely the other colleagues across health and social care, and in GP practices.

### **Special for Service Managers**

Investing in and supporting this workforce – skilled at delivering nursing care in people's homes - is necessary for safe and high quality care in this special setting, since none of the safeguards of a controlled environment, like a hospital ward, are in place.

Staff work out of sight of each other and of team leaders, and in a wide variety of settings. They must travel widely, carry their equipment with them, and safeguard themselves, their patients and the sensitive information they deal with whilst on the move.



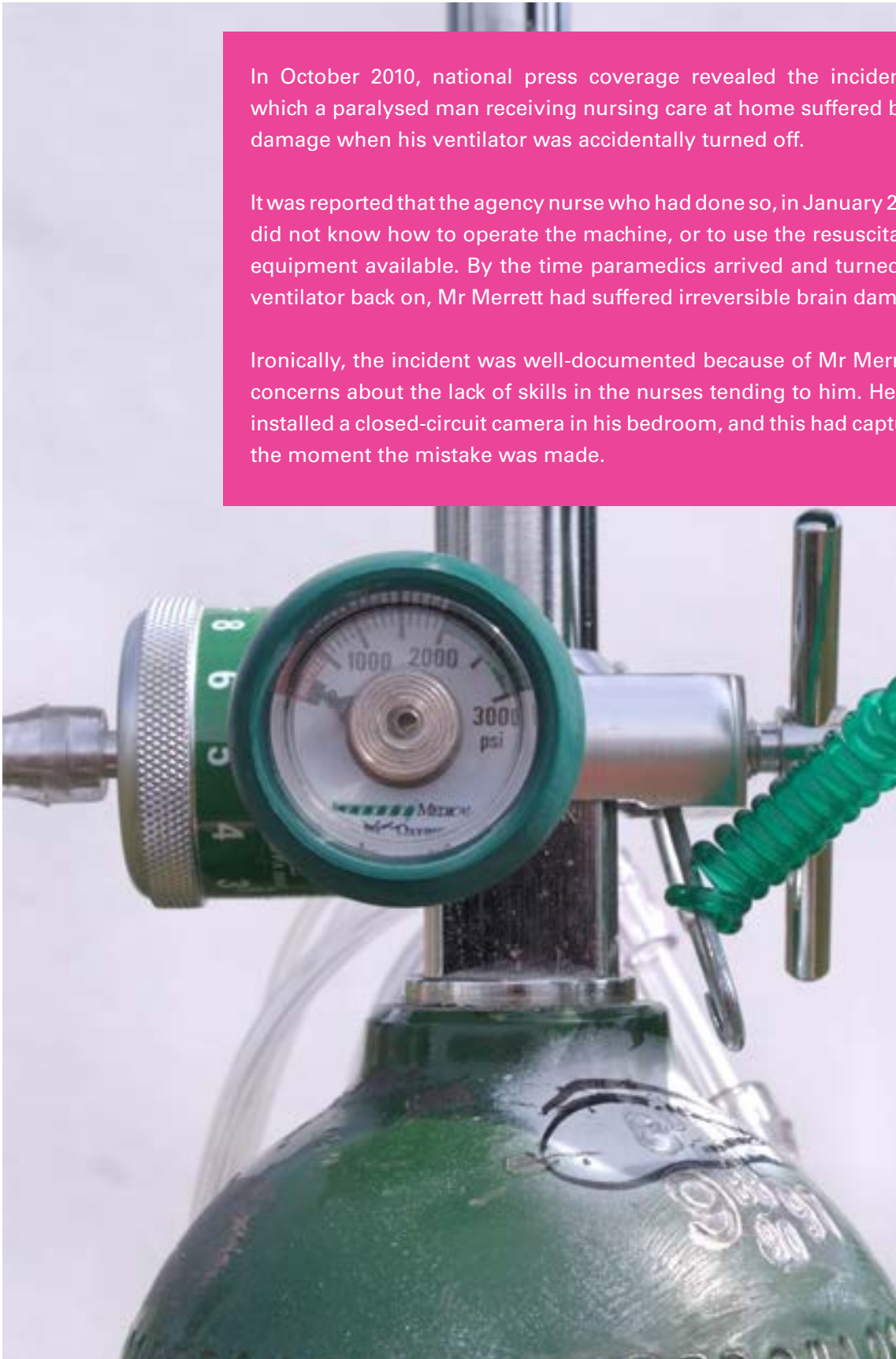
# Jamie Merrett

## A Reminder of the Risks at Home

In October 2010, national press coverage revealed the incident in which a paralysed man receiving nursing care at home suffered brain damage when his ventilator was accidentally turned off.

It was reported that the agency nurse who had done so, in January 2009, did not know how to operate the machine, or to use the resuscitation equipment available. By the time paramedics arrived and turned the ventilator back on, Mr Merrett had suffered irreversible brain damage.

Ironically, the incident was well-documented because of Mr Merrett's concerns about the lack of skills in the nurses tending to him. He had installed a closed-circuit camera in his bedroom, and this had captured the moment the mistake was made.





**Care at Home: Right Nurse, Right Skills**

Community nurses represent the frontline of nursing in the home. They deliver hands-on care, promote and maintain people's independence and provide education, advice and support to patients and their families. The roles and responsibilities of the community nursing team are wide-ranging, and a range of team members with different skills are required to meet all these needs.



Once, teams would have consisted of a district nurse 'sister' and community staff nurses. Now, the team leader in charge may have a different title, and there are new team members. These include community matrons who look after people with complex needs on a regular basis; specialist nurses like Marie Curie nurses who care for some patients who are dying at home, or nurses focused on a specific disease such as Parkinson's disease; and health care assistants or 'assistant practitioners', who work under the direction of nurses to help deliver care.

What is important is that there are enough of the right nurses, with the right skills, to keep patients safe and well cared for at home.

### **The Issue: Loss of Nursing Skills at Home**

The need for skilled home nursing has been steadily rising. One in four people over the age of 75 need a nurse's care at home, rising to one in two people over 85. In total they visit more than 2.6 million people a year. This demand is fuelled by a growing number of older people, the move to discharge people earlier from hospital, and to treat people with complex conditions at homes.

To meet this growing demand, home nursing services have been changing and developing, and introducing new ways of working. An alarming consequence of these developments is the growing loss of nursing skills, and the impact this is having on the quality of care for patients in their own homes.

## Contributing Factors

- ✚ **Falling number of community specialists** - the latest data from the NHS Information Centre illustrated in figure 1 show that the number of trained district nurses has been falling for more than a decade, to fewer than 10,000 in England for the first time in 2009. Even adding in the employment of 1,666 community matrons to the district nurse figure, only brings the total to 11,318 – fewer than the district nurse figure of five years ago.
- ✚ **Increasing use of health care assistants to do nursing tasks** - the number of health care assistants - trained to do specific tasks but who are not qualified nurses - has more than doubled over the last 10 years.
- ✚ **Reductions in the education of community nurses** – there is no requirement to have a specialist qualification for nurses to work in the community. So employers have had the freedom to be flexible about the education and training of the nurses they employ to work in patients’ homes and community settings. Many employers have stopped sending nurses for community training, and district nursing courses have closed in many universities.
- ✚ **Highly-diluted skill mix** - the mix of staff in the community workforce has been changing, reflecting a much greater diversity in the skills in the team, and new ways of sharing the tasks that need to be undertaken. In some places healthcare assistants are now responsible for the delivery of elements of care that would once have been the province of an experienced community nurse, such as tube-feeding patients, taking blood for tests, treating leg ulcers, making complex wound assessments and changing urinary catheters.

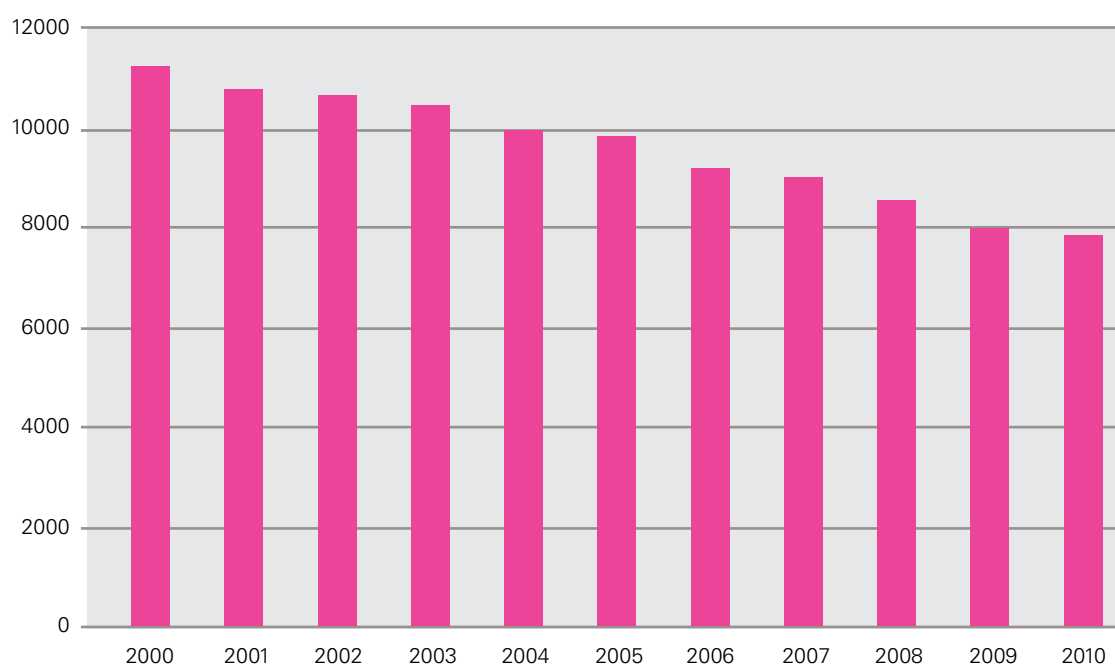


Figure 1: Total Qualified District Nursing Staff 2000-2010 (Headcount)  
Source: NHS Information Centre – Non medical bulletin tables 2000 -2010



## **NHS Reforms**

Current changes to the NHS, set out in the Health and Social Care Bill, will introduce further changes to the provision of home nursing care. 'Any qualified provider' organisation, including charities, social enterprises and independent organisations, will be able to bid for contracts to provide community nursing and other home-based services. The responsibility for securing community nursing services will lie with local clinical commissioning groups; while the local authority will be responsible for the local health and wellbeing plan. Nurse education and training will be planned at local rather than national level.

These changes are taking place in the context of extreme financial pressure, with the NHS as a whole required to make savings in the region of £15-20 billion over the next three to four years. The QNI is already receiving regular reports from community nurses about reductions in staff numbers, down-grading of posts, ending of innovative projects and a rush to retirement amongst nurses who are eligible. Morale is low and practitioners are concerned about their ability to sustain high quality services and care. We are concerned that these measures, and local planning of nurse education, will lead to a 'postcode lottery' in nursing skills.

As one community nurse told us:

"Nurses with little clinical knowledge and experience are being thrust upon the unsuspecting! When patients see a uniform, they presume that the person wearing it is capable of the role but I fear this is often not the case. Experienced nurses are being taken away from front line services to perform a mostly managerial role and at the end of the day many are leaving because they feel so frustrated by this disparity".

## **The QNI – Our Commitment to Patients**

In 2009, the QNI published '2020 Vision – focusing on the future of district nursing'. The report recommended that district nursing was reinstated as the core of nursing in the home so that the quality of patient services could be maintained. In response to the findings, the Council of the QNI agreed to a new strategy with renewed emphasis on the QNI's original aim of improving the care of the patient at home.

On the ground, the QNI is still working with nurses to make change happen through our Queen's Nurses, the nurses in our networks and our innovation project leaders. We are committed to being more vocal in speaking up for patients and getting more directly involved with patients, carers and the general public.

Our first major campaign to improve nursing care at home was launched last October – the **Right Nurse, Right Skills** campaign (RNRS).

More than 3,000 people have already voiced their support. The campaign is not only about district nurses. Nor is it a campaign against health care assistants. The issue of the right skills to match patients' needs applies throughout the health care team, and includes both general support workers, and highly specialist nurses. For this reason, the campaign has already received the support of the Stroke Association, the Multiple Sclerosis Society, Diabetes UK, Macmillan Cancer Support and the British Heart Foundation, as well as Education for Health and the NHS Alliance.

Baroness Sally Greengross, Chief Executive of the International Longevity Centre, who supports the campaign, said:

“The need for skilled home nursing is rising fast as the population ages and people are discharged home earlier from hospital. The care they are given must be given by the right nurse with the right skills, which is why I am delighted to support the QNI in its vital campaign. I would encourage everyone who cares about the quality of nursing that they and their loved ones will receive at home when they need it, to support this campaign”.

Since we launched the campaign, we have received hundreds of stories from the public. Many describe the impact of decreasing skills on the quality of care experienced by patients at home, underlining our fears about what is happening to skills in the community.



## About this Report

This report captures the experiences of people who have received nursing care at home, and people who observed nursing care being provided, such as carers and family members. For many, the experience has been “just wonderful – my nurse was a saviour in a very uncertain time”. But for others, it’s been far from satisfactory: the nurse “rushed in, handled the patient quite roughly, spoke only to carer, and gave poor care”.

The findings show what matters to people in their experiences of nursing care and their nurses. Based on this evidence, actions have been proposed to help drive change for patients receiving nursing care at home. There is no central national survey of patients’ experience of nursing care at home, to match the surveys carried out regularly about hospital inpatients, and patients of GPs. So this report is based on stories and figures we have collected through a range of activities. Important contributors include:

- ✦ **RNRS campaign contributions** - as part of the campaign petition we sought comments from people about nurses’ skills in their local area. People were able to provide this information via the online or hardcopy petition forms. More than 650 people provided comments, some of which are in Appendix A.
- ✦ **Stakeholder Roundtable** - on 2 June 2011, the QNI held a roundtable discussion. We invited senior representatives from 13 patient organisations, healthcare voluntary sector groups and nursing professionals to offer their insights and views on nursing care in the home to help understand the patient perspective.
- ✦ **Nursing Care at Home Survey** - the QNI ran an open-access survey from July to September 2011, to seek the views of individuals, carers and family members about their experiences of receiving nursing care at home. The survey was developed in conjunction with our community nurses and patient networks. The survey was available online or could be requested in hard copy format from the QNI. A total of 265 people responded to the survey. A separate report detailing the full survey results is available on our website.
- ✦ **Interviews** - during August and September 2011, the QNI held interviews with 8 individuals, carers and family members for this report.
- ✦ **Individual service reviews** - the report was informed by a review of the findings from 5 community nursing/district nursing service reviews produced by primary care organisations from around the country, and publicly available on their websites.
- ✦ **Queen’s Nurse working group** - on 16 September, the QNI convened a working group of QNs to review the individual stories collected from the survey and interviews and provide their insights on the reasons for the poor experiences of care and areas for improvement.



**Main Findings: What Matters to People**





Nursing care in the home is vital to support people at home. However, there has been surprisingly little research on understanding the patient perspective, given the shift towards caring for people in their homes.



While many primary care organisations have assessed their own services via periodic patient feedback, and there has been some research undertaken by charities such as the Alzheimer’s Society, the professional view dominates the evidence landscape.

Through our activities we have analysed some of the experiences of patients, carers and family members of nursing care at home and identified a number of common themes. It has been a real privilege for the QNI to understand, capture and share people’s experiences of nursing care at home – their journeys, their hopes and fears.

### **Being a Patient at Home: Their Experiences**

#### **Highly Valued Service**

Our report shows that nursing care in the home is highly valued by the public. For many, it’s the “essential service” which supports their choice to stay in their own home and receive the care and support they need.

As one campaign supporter stated:

“This is one of the most important and needed branches of health care. My own parents, other relatives and friends were all lucky enough to be cared for by home care nurses. The value of this care in their own home cannot be measured. It was excellent and the trauma of severe illness was kept to the minimum by being in their own home, being looked after by genuinely caring people.”

#### **Many Positive Experiences**

Overall, the experience of home nursing care is well received by respondents to our survey – with just over 70% rating their most recent experience of home nursing care as ‘excellent, very good or good’.

Specifically, 31% of respondents rated their home nursing care as ‘excellent’. Interestingly the vast majority of these respondents received their care from a registered nurse only. Another 24% rated their most recent experience as ‘very good’ and 17% as ‘good’.

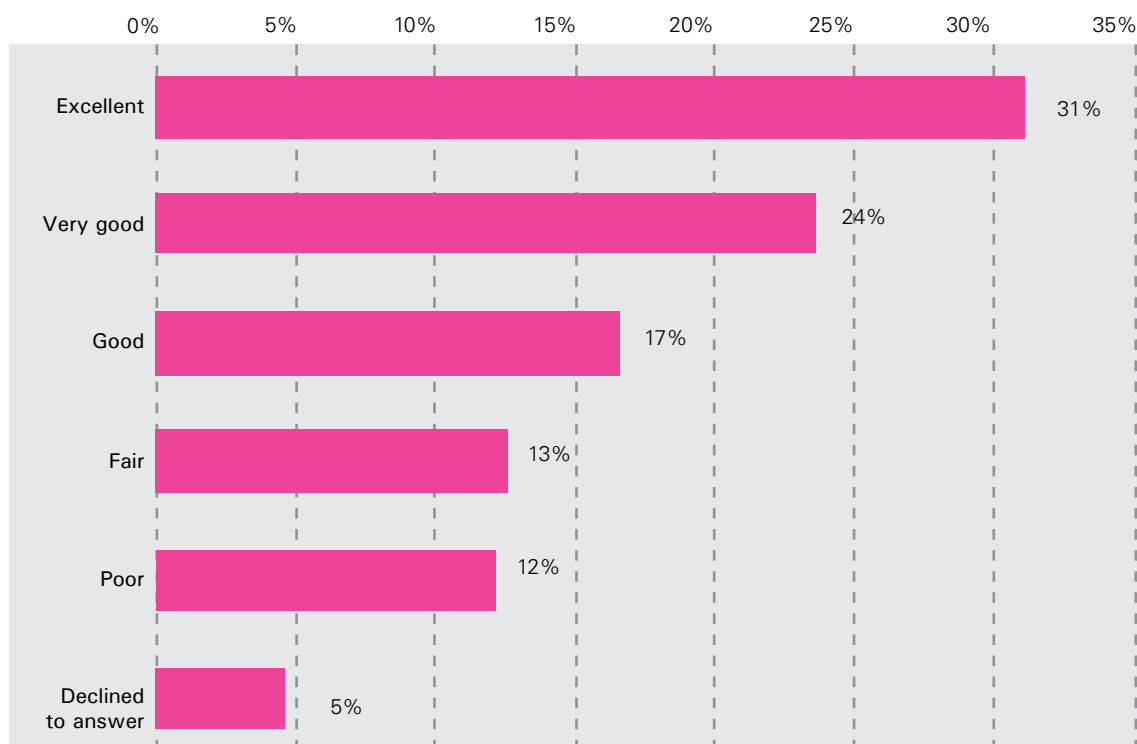


Figure 2: Experience of home nursing care

Respondents to our survey were also very positive about the support they received from their nurse/s. The statements that received the highest response to 'yes definitely' were:

- ✚ I was treated with dignity and respect - 122 responses
- ✚ I felt safe in my home when receiving nursing care - 116 responses
- ✚ I was able to ask questions, voice concerns and talk openly about my care - 105 responses

Our analysis of district nursing service reviews reinforces this sentiment. It shows that most people have an excellent experience, with the overall trust and confidence in the home nursing service being 'high'.

- ✚ 83% of total respondents rated their experience of seeing a district nurse as 'good', 'very good' or 'excellent'
- ✚ The overall satisfaction of the service is high with 65% of patients rating the service as 'excellent' and 27% rating it as 'very good'
- ✚ 71% of patients said that their quality of life had 'improved a lot'; and a further 20% said that their quality of life had 'improved a little'

#### Far from Satisfactory Experience for Some

For 25% of survey respondents, the experience of nursing care in the home did not meet their expectations resulting in a poor quality service. This consisted of 13% rating their most recent experience as 'fair' and the other 12% rating their experience as 'poor'.

From this group of respondents, concerns focused on two areas: nurses' involvement **and their** abilities. The statements that received the highest responses to 'no, not all of the time' were:

- ✦ I was treated with dignity and respect - 40 responses
- ✦ I felt safe in my home when receiving nursing care - 31 responses
- ✦ I was able to ask questions, voice concerns and talk openly about my care - 27 responses

This finding is illustrated by the experience of one survey respondent:

"My mother suffers from dementia. Most nurses that call to dress leg ulcers or take blood for testing seem to have little or no understanding of the illness and either talk to her like she was a 2 year old or ignore her completely addressing only the carer. One occasion I had to intervene because Mum obviously did not understand what was required of her and the nurse was twisting her leg in an unacceptable rough manner. The same nurse also told her not to make such fuss when Mum reacted to an iodine dressing being put on an open leg wound."

Our analysis of district nursing service reviews picked up some additional concerns around:

- ✦ **Communication** – some people found it quite difficult to talk with their nurse. Often patients indicated that at some stage staff had talked about them "as if they were not there"
- ✦ **Time** – some people felt that they either would have preferred more time to discuss their problems with the nurses or they wished that the visit could last longer
- ✦ **Information** – nurses did not have all of the necessary background information on the patient
- ✦ **Continuity of care** – consistently, people expressed their desire to have some kind of continuity of service (e.g. with the same nurse visiting them for a period of time)

#### Mixed awareness of who's coming to visit

For many survey respondents, the nurse/s that came to visit were seen as the "invisible army" delivering a vital service across the community. Nevertheless, the awareness of patients, carers and family members about the different nurses who come to visit is clearly mixed.

Figure 3 shows that fewer than half (43%) knew that the nurse who provided care was a registered nurse. Another 33% knew that the team that provided care was a mixture of professionals. Disappointingly, 14% indicated that they didn't know which type of nurse/s cared for them.

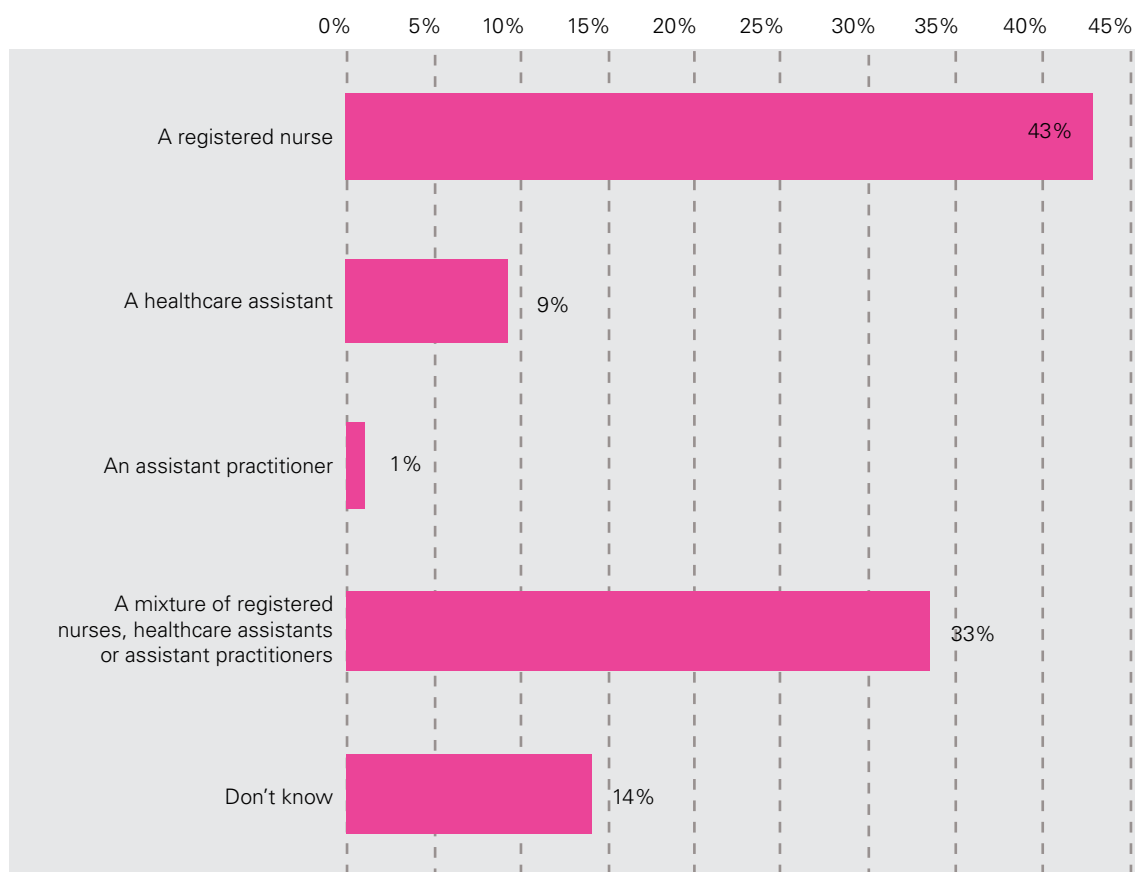


Figure 3: Was the nurse/s who cared for you..

Here's what one nurse had to say about patient awareness:

"More and more qualified nurse tasks are being transferred to nursing assistants. Patients really do assume that they are being treated by qualified nurses, and nursing assistants and community nurses have given themselves the title 'district nurse'! How misleading in this? District nurses are slowly losing their identity."

One of our campaign supporters makes an interesting observation:

"Nurses should be assisted by support staff and there needs to be a distinction between a Nurse and an Assistant. In the US the distinction between a Nurses' Aid, a Registered Nurse and a Nurse Practitioner are clear. The public knows what to expect from each role, as do other healthcare professional colleagues."



## Skills: Do They Make a Difference?

Our report shows that for patients, carers and family members, there is a distinct difference in the quality and experience of care and support they receive at home when it is provided by a skilled nurse. From the patient perspective, the demonstration of technical skills by a healthcare professional suggests to the patient that they are being looked after by someone who is trained and practices to the highest standards.

Here is one family member's observation:

"The DN who cared for my mother (in-law) was just superb. She was so calm, caring and discrete. She asked all the right questions and just knew how to put us all at ease. It was like she was able to read our thoughts. Her kindness and intelligent caring meant mum made an excellent recovery. She prescribed new medication and cream for her legs. She assessed her chest and breathing and explained everything. What a difference from the care we had in the hospital."

Overwhelmingly, respondents to our survey considered 'skills' as an essential characteristic of their nurse/s. This was expressed in a number of different ways; capabilities, approach and attitude. More than 90% of respondents considered the statement, the 'nurse understands my treatment', as very important. Both the statement 'nurse listens to me and works with me' and the 'nurse is caring and compassionate' were considered very important by 84% of respondents. A further 75% of respondents rated the statement the 'nurse responds to my needs quickly' as very important.

We also found that patients, carers and family members make an implicit assumption that nurses are educated and trained to the required standards – they are not looking for qualifications, certificates or even titles. Rather, they expect their nurse/s to demonstrate key skills when visiting them at home, which are focused around:

- ✦ Competence – is my nurse up to the task?
- ✦ Confidence – is my nurse able to handle my home environment?
- ✦ Caring – is my nurse able to relate to me as a person?

### Competence – up to the task

Our report shows that patients, carers and family members value nurses that are up to the task; they are competent to provide nursing care within their home.

Figure 4 shows some of the nursing skills that were important to our survey respondents. In terms of competence, the most supported statements were: 'can assess unexpected situations and take appropriate action' (69%); 'coordinates other people and service to help with my care'(60%); 'keeps me informed, answers questions and offers advice about my treatment'(57%); and 'explains procedures, clinical conditions, test results and medications'(49%).

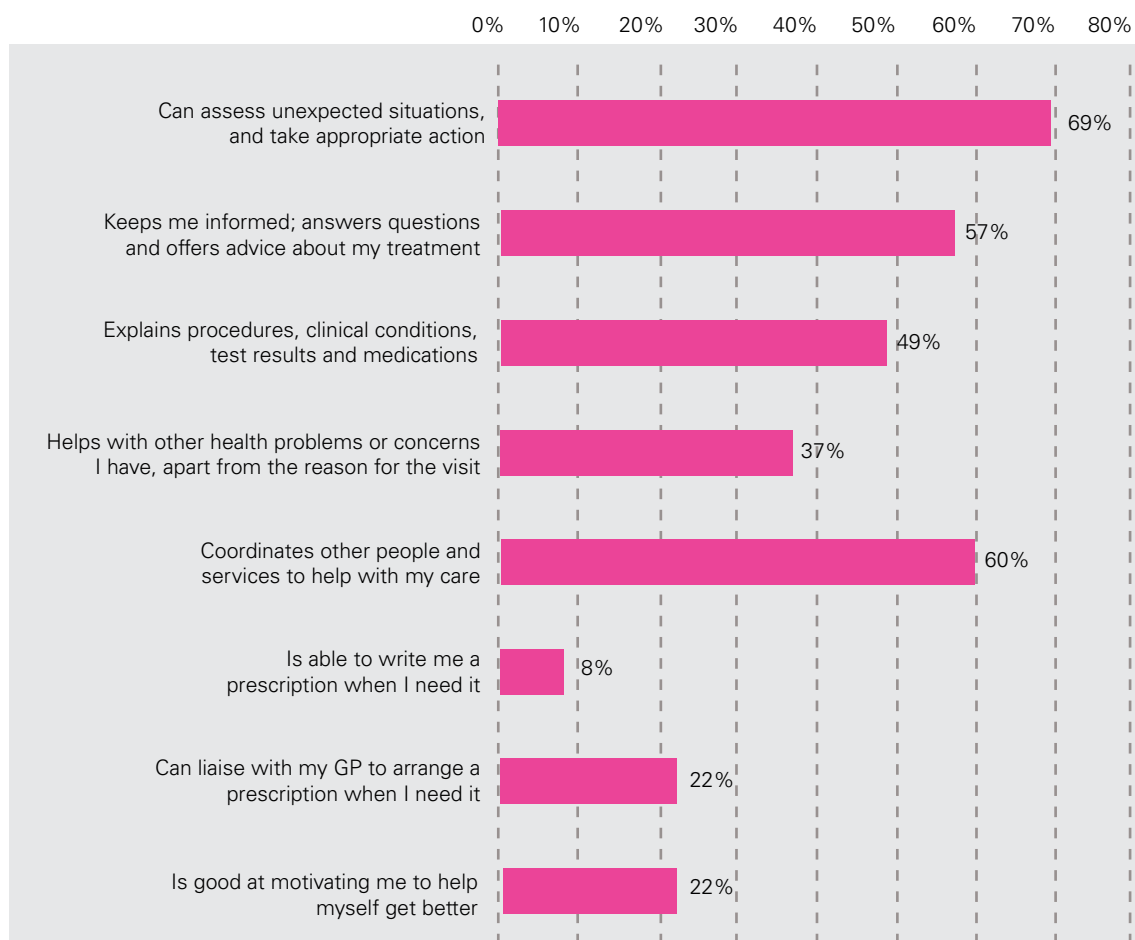


Figure 4: Nursing skills important to patients

Specifically, we found that nurses who demonstrated a competent approach have three key traits:

1. **A good knowledge of a patient's illness, treatments and support systems** - they understand the patient's condition including their history. They can talk about treatments and drugs and explain what to expect. They are aware of other services available to support the patient.
2. **Interventions, treatments and procedures are performed properly** - the procedures that are performed are done well, e.g. 'bandages were comfortable and lasted until the next visit'. They are confident in identifying new problems as they arise. They follow appropriate health and safety requirements.
3. **Ability to co-ordinate care services and manage on-going care** - they help patients stay at home by organising other care services. They understand how to work with other agencies such as social care. They use the care plan to communicate with others about on-going patient needs.

Unfortunately this was not always the experience for patients. We uncovered numerous examples of nurses lacking basic skills, necessary for nursing care tasks. The observations from our patients, carers and family members focused on:

- 1. A lack of knowledge about conditions and treatments** - they didn't understand the patient's condition. They did not properly assess the patient's needs. They didn't read and/or use care plans. They did not adequately signpost patients to the right information sources.
- 2. The display of poor practices** - they were hesitant when performing procedures and not always successful, e.g. 'my bandages were too tightly applied and had to be removed due to the pain which they caused'. They did not clean up after treatment. They continued to bring the wrong equipment. They didn't clean their hands.
- 3. Difficulties with communication** - they were difficult to talk to. They talked about patients "as if we are not there". They found it hard to approach difficult subjects. They were unable or unwilling to answer questions.

The consequences for patients varied from minor incidents to major concerns: from discomfort to distress, unnecessary pressure sores, additional hospital admissions and unrelieved pain for dying patients. Pages 30-35 feature three families' stories and some observations from our Queen's Nurses.

#### Confidence – in a unique environment

Patients, carers and family members highly value nurses that demonstrate a confident approach in performing their roles and responsibilities. Confidence was not about superiority, for patients it was about their nurse being at ease with them, their treatment and their home.

This is reflected in figure 5, which shows how patients value their nurse/s attitude.

Nearly 58% supported the statement 'say they do something, and actually follow through and do it', 48% supported the statement 'not rushed, take time with me', and 46% supported the statement 'positive attitude toward their work; appeared to like their job'.

These results are coupled with 26% directly stating that the most important attitude a nurse should have in providing care and support at home was to be 'confident'.

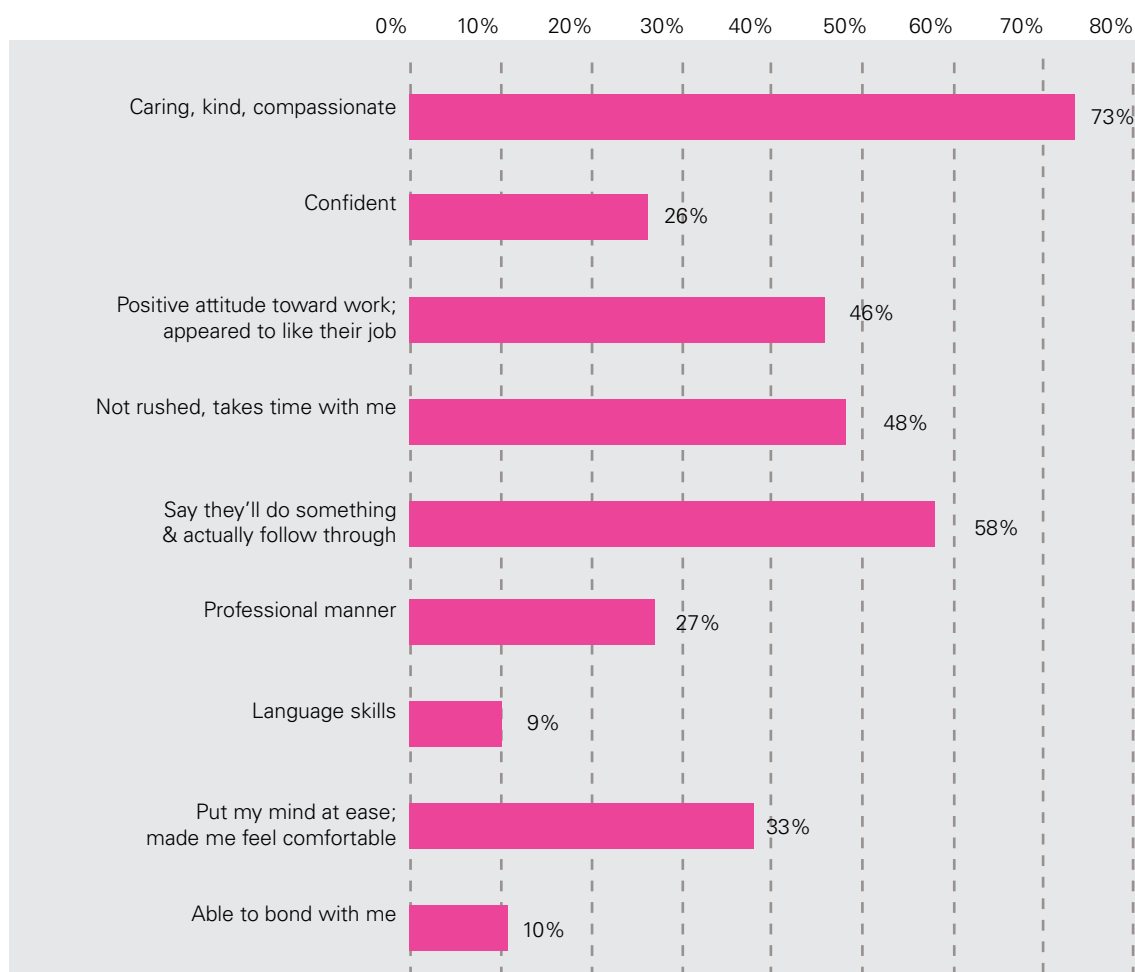


Figure 5: Attitudes of nurses important to patients

People receiving care in the home suggested that the central elements of a confident approach are:

1. **Poise** - they speak with authority and certainty - they carry out treatment efficiently and skilfully while showing care and concern for a patient's condition. They are able to work quickly without appearing rushed in any way.
2. **Trust** - information and advice is delivered with honesty - they are helpful. They are honest about things that they cannot do and what they will do to get the appropriate care.
3. **Character** - proud and professional - they are well presented with a professional manner. They show enthusiasm for their job. They have a great approach - friendly with a good sense of humour.



On the other hand, some patients had experienced nurses who lacked confidence and were clearly anxious about being alone in a person's home. For patients, particular issues were nurses who were:

- 1. Not reassuring and lacking in professional confidence** - they gave no reassurances to put patient at ease. "They were mostly the newly qualified youngsters who were nice enough but just lacked life experience." They found it hard to approach difficult subjects. They had more confidence than ability.
- 2. Rushing to complete the 'task'** - they were rushed in the care given. They gave no time to explain things. They seemed disinterested. They questioned the care. "They rushed, not in control of what they are about." Patients believed this stems from two factors: the system overwhelming individuals with demands, at times conflicting; and individuals' inability to prioritise and focus on the essential.
- 3. Disinterested with the patient and their job** - they didn't enjoy their work and made no effort to understand the needs of the patient - only interested in doing the bare minimum standard. They felt it was just a job they did, "didn't want to bother answering questions and couldn't wait to leave." They were complaining about their job. They looked scruffy.

#### Caring – for me as a person

The personable aspect of being a nurse – caring – is clearly the skill most valued by people being cared for at home. As figure 5 illustrates, 73% of respondents to our survey nominated 'caring, kind and compassionate' as the most important skill their nurse/s should demonstrate.

From the perspective of the patients, carers and family members, a nurse who demonstrated a skilled approach to caring would:

- 1. Take their time to understand the person** - they consistently make the effort to understand the needs of the patient and adapt to those needs. They listen and take the views of patients, carers and family members into consideration. They are able to anticipate a patient's needs and feelings.
- 2. Show compassion for the situation (both patient and carer)** - they are sensitive about a patient's illness and treatments. They listen and show empathy, understanding and support. Kindly explain the implications of not following instructions and taking medication. They also concern themselves with the well-being of the carer.
- 3. Go the extra mile for their patients** - they act as the patient's advocate, championing issues and concerns with others. They encourage a patient's recovery and encourage patients to better health. They also display an attitude of "nothing is too much trouble".

In contrast, many patients had experienced nurses that displayed poor caring skills. Particular issues were:

- 1. Did not listen** - they made promises they did not keep. They did not take into account what the patient and/or carer was telling them. They were reactive not proactive.
- 2. Showed little compassion** - their attitude towards the patient was insensitive with little care for the person. They were not able to empathise with the patient and would not alter their behaviour appropriately. They were dismissive of the carer's concerns/needs.
- 3. Focused on performing the task only** - they made no effort to understand the needs of the patient - only interested in doing the bare minimum standard. They seemed to work to a "tick list", and did not reflect on what they were doing or around them. They did not provide holistic care.

### **Summary**

The findings are clear. When nursing in the home is done well, and delivered by nurses who are competent, confident and caring, it transforms peoples' lives at very difficult times. Patients and their families recognise and value the expertise of community nurses who have poise and speak with authority, engender trust, and are proud of their profession and their practice.

We know that nurses and service managers aim to provide good care to patients. The examples of poor care in this report are clearly not acceptable. We cannot say categorically how common or uncommon they are, at national scale – but even a few instances of poor care are unacceptable. For each individual patient, it is their personal experience that matters, at that time, and with that nurse. We may not have a second chance to get care right.

There are many challenges in the system that put pressure on community nurses. They are working in a health system undergoing huge changes, and with tremendous pressure to find financial savings. Demand for home care is rising, but skill mix is diluting the expertise available to meet demand. There has been a lack of investment in training for the special skills to nurse in the home.

Listening to what patients, carers and families have told us, the QNI believes that this is the time when everyone – nurses, managers, commissioners and policy makers - must take action to prevent the loss of one of the most precious assets in our health care system: expert nursing in the home.

# Queen's Nurses ++++++

Committed to Quality Care in the Home



The QNI re-introduced the title of Queen's Nurse in 2007, nearly 40 years after it was last awarded.

Our network of QNs is ensuring that standards of care in the community are continually protected, improved and developed, to the benefit of individuals and communities.

Today's QNs include district nurses, community matrons, health visitors, practice nurses, specialist nurses, nurse educators, nurses working in prison, nurses working in areas of learning disability, paediatrics and mental health. They work for the NHS, charities, schools and independent organisations.



# Competence



“My mother had polio 50 years ago. When my father died – my mother’s carer – she realised to stay at home she would need help. The district nurse team supporting her for the first 6 years was excellent: managing her continence problems well with a catheter; her tissue viability remained good even though she spent about 12 hours a day in a wheelchair; and had a suitable cushion in her wheelchair. However, everything changed when there was a major reorganisation of the district nursing service.

As a family, we had **constant problems trying to contact the nurses**. For example her cushion was worn in the middle and we wanted her to have a new one. **My sister tried phoning, I tried writing, and we both tried visiting their office**. We eventually got hold of the service manager who said they were having “difficulties”! Eventually she bought a cushion herself. The real problems started 6 months before my mother died. The district nurse turned up on a Friday afternoon and removed my mother’s catheter - **no discussion, no explanation**. She **did not provide any incontinence pads** so the carers had to scrounge some from their other clients until we could buy some. After many phone calls the district nurse turned up 3 weeks later and agreed that my mother needed incontinence pads supplied regularly.

But **the damage to her skin had already begun**. The carers monitored her skin carefully and reported every change to the district nurses but got little support. There was **no tissue viability assessment** in her nursing notes. I asked them to review the mattress she was using as she was unable to turn herself in bed and her skin was clearly deteriorating. Out of desperation, my sister persuaded a surprised but helpful social services manager to authorise the delivery of an airwave mattress. Two weeks before Christmas my mother had a **grade 4 sore on her sacrum** and the district nurses were visiting once, and occasionally twice a week to dress it. The carers were left to dress it in between.

By the Christmas weekend **it was clear that my mother was dying - though you would not know it from the nursing notes** and there was no plan for the nurses to visit over the weekend. My mother was **in pain and distressed**. I had to contact the out of hours doctor for some analgesia for her - still no sign of the nurses. I then phoned the on call district nurses and 2 very caring and efficient nurses arrived and they took control of the situation. By the time they left my mother was calm, comfortable, dressing had been changed etc and they assured us that they would send her usual district nurse the next day but we could call them back if we needed them later in the day.

**Fortunately my mother died peacefully** that night and **we didn’t need to call any more nurses**. We never did see her usual district nurses - **no post bereavement visit of any kind**. I still have the nursing notes they didn’t bother to collect. Nor did they collect the mountain of continence supplies in the house, but I managed to find them good homes.”







"No provision for end-of-life care. This would have anticipated issues around pain management."

"No plan for nurses to visit. Left up to carer to chase."

"No use of care plan to communicate patient needs."

"Excellence in care declined."

"Clearly the re-organisation led to poor practices, communication and culture."

"Good practice for DN services is to have named nurse for contact."

"Need stronger leadership & management to address issues."

"Failed to communicate."

"Even if they didn't have any pads on hand they should have followed up immediately."

"Nurses must aim to explain decisions."

"This situation is neglect."

"No one should have a grade 4 sore from this situation."

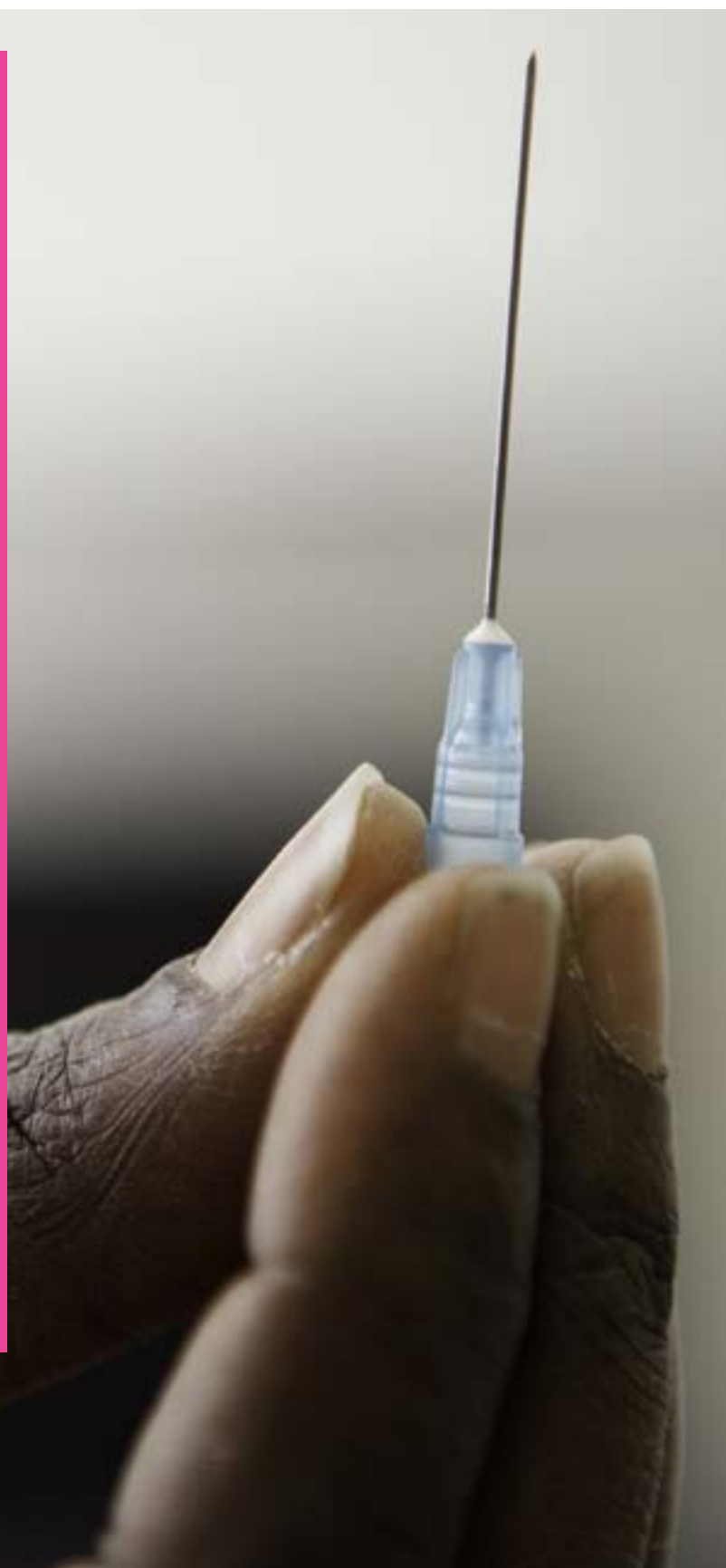
"A holistic assessment – including tissue viability – with follow through in the care plan would have prevented this from happening."

"This action does not follow the end-of-life care pathway."

"Symptom of poor practices."

"This culture of neglect becomes the norm."

"Just like Mid Staffordshire."



# Confidence

## Patient Voice/Queen's Nurse Commentary

"My dad was recently discharged from hospital and was being looked after by the home nursing team after a stroke.

On this one day a nurse came to visit to change a dressing. However my dad was very poorly. On this occasion the community nurse took his temperature (via his ear) and **expressed surprise at the low temperature but dismissed this as being due to a faulty thermometer.** I then took dad's temp with my thermometer and it also showed a low temp but I couldn't be sure I had taken the temp properly (under the tongue).

The **nurse said that, if dad's temperature was really that low, he would be dead.** The next day, I had to call an ambulance and the paramedics confirmed that **dad had hypothermia** and dad was taken to hospital. The medical staff I met the follow day were very surprised that the nurse had not done anything the day before.

For me it was not a lack of compassion, not negligence but **lacked an awareness to follow through.** My expectation is that if you are home visiting – and working in isolation – you should call for a second opinion if you are unsure.

The nurse needs to be both – caring and compassionate with knowledge. They also need to be able to assess the whole situation. I concluded that she didn't appreciate the implications of such a low temperature - because of **limited knowledge.**"





“Didn’t follow up – lack of insight”

“Make a visual assessment and make a judgment”

“Look for signs from patients”

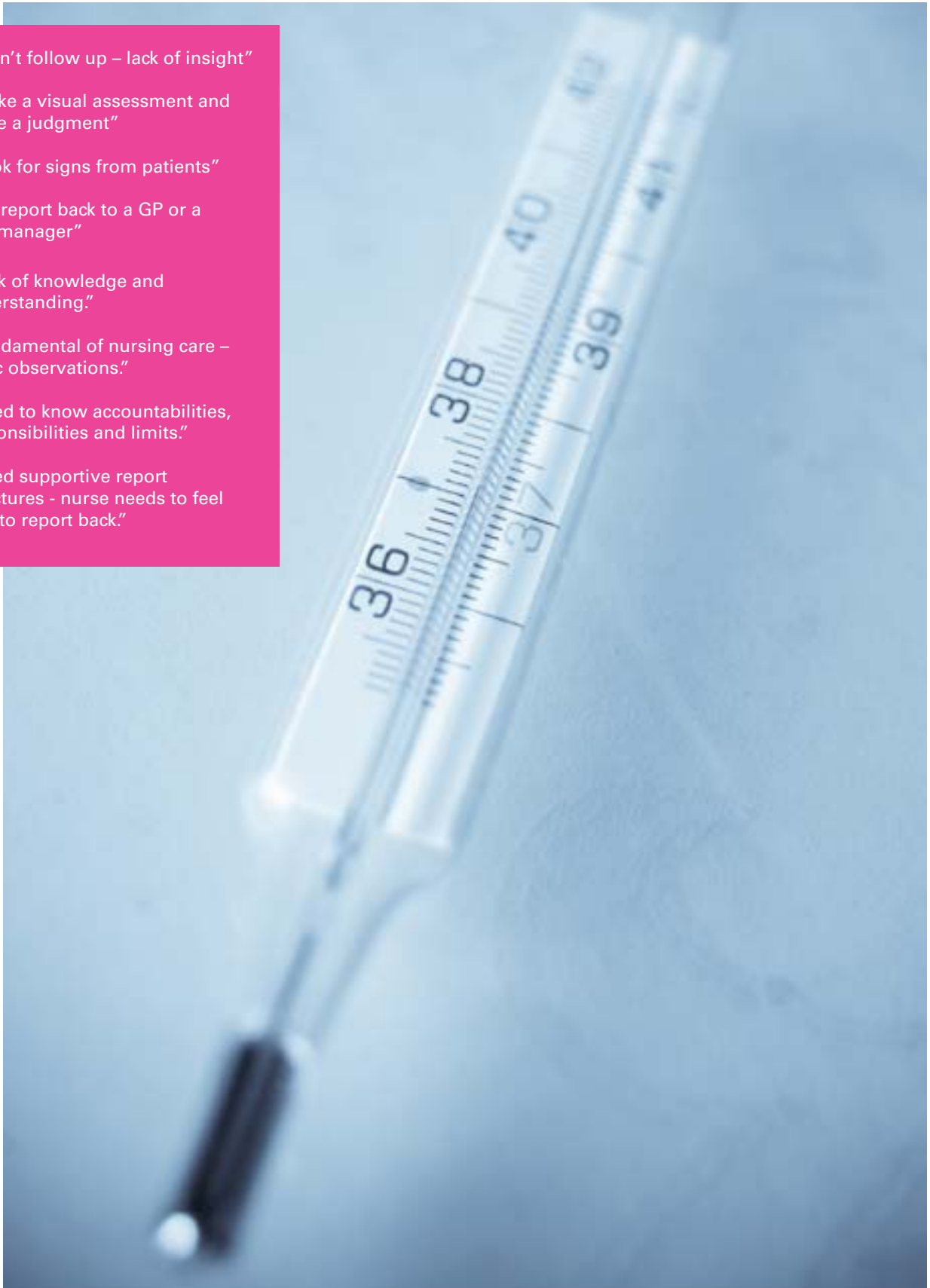
“No report back to a GP or a line manager”

“Lack of knowledge and understanding.”

“Fundamental of nursing care – basic observations.”

“Need to know accountabilities, responsibilities and limits.”

“Need supportive report structures - nurse needs to feel safe to report back.”





"My mum is in her late 80s and very frail with limited mobility. She lives on her own - with daily help from social services to manage her personal care needs.

I had noticed she had become very constipated which concerned me. I contacted her doctor who advised me that they would ask the district nurse to visit and administer an enema.

When she arrived she did a lot of talking and not much listening. **She asked no questions about my mum – clearly no interest and seemed in a rush.** There wasn't even a basic assessment of my mum's needs. I don't think she was very experienced.

All she was interested in doing was administering the enema. But she **did not even bother to wash her hands** before or after administering micro enema or take off her cardigan.

As I was present, she decided she could go - **nothing was negotiated.** I was completely baffled as she didn't stay until the results. This didn't provide me or mum with any reassurance. **Her approach frightened me.**

Since this episode, the GP has prescribed enemas which I administer if required. Thankfully, this hasn't been for some months.

I have managed to keep Mum's bowel regulated with firm monitoring of fluid/food intake and a regular dose of Movicol.

She just wanted to be in and out of mum's home quickly. **Basic dignity and compassion were missing."**







"The episode was very dangerous. She could have created untold damage to this persons bowel and an elderly person may even have gone into shock following administration of an enema (even a micro one). This was actually negligent:

- Where was the prescription for the micro enema?

- Where was the documentation following the administration?

- Where was the follow-up?"

"No professionalism... and still very task orientated."

"There is a lack of understanding of basic assessment; the issue of constipation; the education that should have been delivered about bowel management; poor communication skills; infection control (hand washing and cardigan)."

"If time pressure didn't allow her to stay should have followed up with a phone call later in the day."

"Much of this is taught at student nurse level and certainly would be at district nurse specialist level."

"The general public will always see any nurse in the home as being the 'District Nurse'!"





**Actions for All**





The QNI believes that high quality community nursing is the solution that will enable the NHS to meet the needs of an ageing population, and a growing number of people with long term conditions, in the years ahead. There is no alternative workforce to help develop, commission and deliver nursing care services in the home, so it is essential that action is undertaken at all levels.



### Required Action

- ✦ For the **QNI**, it is about helping patients, carers and families to get the best from community nursing services; and helping nurses to become competent, confident and caring practitioners.
- ✦ For **commissioners**, it is about providing communities with a high quality service underpinned by a skilled workforce.
- ✦ For **organisations employing community nurses**, it is about ensuring that they have an appropriate workforce skilled to nurse in the home setting - minimising the inherent risks and enable high quality care to be delivered.
- ✦ For **nurses** and **nursing teams**, it is about taking pride in, and professional responsibility for, the care they are delivering.
- ✦ For **patients**, **carers** and **family members**, and the groups that represent them, it is about a partnership with the professionals to achieve the high quality care they deserve.

## **Commitments from the QNI**

- 1.** Work with patient and carer groups to develop a range of information resources for patients, carers and family members. This will include:
  - ✦ A set of frequently asked questions on nursing care at home
  - ✦ Information to help people ask their healthcare professional the right questions
  - ✦ A checklist to help people be confident about receiving nursing care at home
- 2.** Launch a national awareness campaign to raise the profile of nurses working in the home.
- 3.** Encourage hundreds more nurses to become a Queen's Nurse – committed to high standards in community nursing.
- 4.** Create a micro-site on 'Nursing Skills in the Community' aimed at helping employers and clinical commissioning groups. This will cover good practice, managing risk in the home, skills audits etc.

## **Recommendations for patients**

- 1.** Patients and families should use the 'Being at Home Checklist' – top tips from Queen's Nurses about being a patient at home.
- 2.** Patients and families should not be afraid to ask for the care they need or to question their community nurse.
- 3.** Patients and families should take opportunities to give feedback, praising good care and alerting to poor care.

## **Recommendations for commissioners**

- 1.** To manage the risks associated with providing home nursing services and to achieve the outcomes for a high quality service, commissioners should require providers to have in place a comprehensive training and development framework for their workforce and also have on-going patient involvement in the development and monitoring of the service.
- 2.** Service commissioners should set standards for community competencies to be held by all team leaders or people in key posts, as part of the appropriate contract for community services with service providers.
- 3.** Education commissioners should increase the number of nurses with specific training for the community working outside hospitals year-on-year.

## Recommendations for employers of community nurses

1. All nurse team leaders should have specific community training so that they can ensure patients receive safe and high quality care in the home.
2. All nurses should receive skills training to match patient's needs – regular skills audits should be used to identify needs.
3. Organisations should invest in understanding the patient experience so that they are aware of poor practice and can benchmark performance with the aim of driving up quality.
4. All nurses new to the community should have a programme of support during their first six months.
5. Provider organisations should include information on the community qualifications of team leaders and key post-holders in their information available to the public.

## Recommendations for nurses and nursing teams

1. All nursing teams should carry out regular audits of their skills to ensure they match patient needs.
2. Nurse team leaders should carry out appraisals to respond to issues promptly and support good care; and ensure nurses new to the community are adequately supported.
3. Team leaders should aim to increase awareness amongst the public of the team and their role and responsibility to help the patient know who is coming to visit.
4. All community nurses should consider becoming a Queen's Nurse, as part of their aspiration to be competent, confident and caring.

## Implications for policy

The future is well known: an ageing population, with more people living with long term conditions, and more complex care being delivered in the home.

This is coupled with a changing service landscape, where care will be delivered by community nurses working across the NHS, charities and independent organisations, in increasingly diverse teams. Safeguards need to be embedded in the system to ensure that high quality care is maintained, and the risk of poor patient care is minimised, as services change.



Additional safeguards recommended are:

- ✦ **System integration**, which is enforced rather than voluntary. Our research shows that patients continue to experience a system with little or no integration across health and social care – as demonstrated through the many examples of patients managed by their “circle of friends”. We support the National Voices’ Principles for Integrated Care which meets patients’ needs and urge clinical commissioning groups and service providers to follow these principles.
- ✦ **System and professional regulatory frameworks**, that set standards for care and for people delivering care:
  - ✦ Our findings shows the huge variation in the quality of care that patients experience when at home. This variation is clearly unacceptable. We are renewing our call for the regulation of health care assistants, to help them play a full and accountable part in the delivery of care. Health care assistants (HCAs) and assistant practitioners should be regulated under a national scheme, work to a Code of Conduct and have regular appraisals including personal development plans.
  - ✦ The Nursing and Midwifery Council should consider introducing a new nursing qualification on a level between Band 4 HCA/Assistant Practitioner and the current registered nurse, to recognise and regulate the nursing care given by skilled HCAs, and to enable them to progress into the nursing profession without undertaking a degree course.
- ✦ **National oversight** of local workforce education and training plans, to ensure that there is an adequate and growing supply of skilled nurses to work in the home. We heard that the skills of nurses practising in the home setting are variable. Recognising that the home is a special place for nursing practice, the QNI believes:
  - ✦ Specific programmes of preparation to work in the community should be available for all nurses moving from hospital or other settings into the community
  - ✦ A minimum preparation for this transition should be mandatory for NHS nurses
  - ✦ The Nursing and Midwifery Council (NMC) and other stakeholders should explore how best to recognise community qualifications and skills on the Register, so that employers can identify people with the right skills to lead teams
  - ✦ Workforce planners and education commissioners should increase the number of nurses with specific training for the community working outside hospitals year-on-year

Finally, we have found that the collection of data on the patient experience of nursing care at home is extremely limited. Improvements in quality will only be delivered if data is regularly collected, evaluated and made available to both employers and commissioners. We call on the Department of Health to institute a regular national survey of patient experience of community services, comparable to the national inpatient survey, through which commissioners and local people can hold service providers to account for the quality of care.

With these recommendations, we believe that the home can remain a safe and very special place for people to receive their care.





**Appendix A – Comments from Nurses and Patients**

## Theme

## Comments from supporters of RNRS

Declining education for community nurses

'I personally have seen de-skilling of the Specialist Clinical Practice role/qualification [which is] totally disregarded when appointing new clinical leads. I have not seen any secondment to training.'

'Band 6s are being recruited without the degree in community health, resulting in a potential stagnant workforce and a watering down of those skills that vulnerable needy patients require.'

'Resent recruitment of community staff nurses in my area being an example two weeks induction and there you are a district nurse as they call themselves it is dangerous and the general public have a right to a workforce fit for purpose with correct leadership guidance and monitoring of skills. I was recently told by a home carer that she will soon be doing my job!'

'As a nurse I'm sad to say that in my local experience there has been too much 'dumbing down' in skills – now too generalist at the expense of the specialist.'

'Dumbing down' of workforce

'Junior staff are unaware of the skills they lack and there is lack of capacity within the system for adequate supervision to be provided.'

'We're seeing more junior nurses being employed within the community setting who don't seem to have the confidence and experience to work in isolation. I have concerns about how this will impact the quality of care delivered, we seem to have lost our experienced nurses.'

'I'm a nurse & commissioner. If QUIPP is to be successful, investment is required in developing the skills of community nurses & leadership for community nursing, which is not being considered strategically as part of clinical commissioning.'

'There are too many unskilled people looking after the elderly in the community. When a crisis happens they are not equipped to cope. They may be very caring, but that does not compensate for good training.'

'I have experience of working with nurses who have 'inadvertently set clients up to fail' causing deterioration in their conditions.'

'More and more qualified nurse tasks are being transferred to nursing assistants. Patients really do assume that they are being treated by qualified nurses, and nursing assistants and community nurses have given themselves the title 'district nurse'! How misleading in this? District nurses are slowly losing their identity.'

'The reduction in District Nurse trained nurses, the employment of very inexperienced band 5 nurses – sometimes newly qualified – and the transfer of tasks, such as giving insulin, to support workers is depriving patients of expert clinical nursing. In the area of palliative care, community nursing has abandoned its commitment to the personal care of dying people.'

'Managers and commissioners must be aware that often it is NOT cost effective to attempt to devalue the role of the Registered nurse by skill mixing inappropriately to save a few pounds on salary costs. This often leads to tasks being performed by non-qualified personnel rather than holistic management of the patient.'

'Many clinical leads have been appointed that have little community experience and/or do not hold any relevant community qualification. I see this as a de-skilling of the profession & chaotic leadership with very little caseload profiling or management experience and skill. I observe this as destabilising many teams.'

'Nursing skills have been eroded and roles which have traditionally involved community nurses have been spread among semi-qualified staff.'

'In essence patients under these teams NEVER come into contact with a district nurse and have access to specialist skills and knowledge. This practice is both dangerous and unfair to patients and their families.'

## Theme

## Comments from supporters of RNRS

'Dumbing down' of workforce (cont'd)

'We have a high concentration of newly qualified nurses working in the community in our area, whilst I support their direct community employment I worry because many of them do not have the required level of critical thinking, or they are extremely task focused and miss important information.'

'The talk of skill mix always means replacing experienced or trained nurses with untrained or inexperienced staff.'

'Our last two community nurse posts were filled with newly qualified staff nurses. Some core skills were missing in their training. For example, one had never done an intramuscular injection, catheterisation and had limited experience of wound dressing ... it was difficult for the rest of the team as they were nervous working weekends, doing on call for terminal patients, dealing with syringe pumps, PICC lines. Their lack of experience was a huge challenge in the community setting.'

Increasing reliance on health care assistants

'We now have less RNs and more Band 4 nursing assistants, while they are 'trained' to perform a certain task e.g. insulin administration, catheters etc, they don't have the full knowledge and skills to carry out an holistic assessment of the patients needs. Also patient DO NOT understand the difference in the roles and often assume they are being treated by a RN!'

'When a skilled nurse retires they are not being replaced by a person with the proper community skills. The situation where health care assistants have visited some of my elderly patients and introduce themselves as 'nurses' is a deception and causes confusion for the patients.'

'These staff [HCAs] are very committed and work hard, however, even after many years experience it is obvious that some do not have the insight or skills required to carry out comprehensive assessment and care planning that is needed to provide appropriate care to those on their case loads.'

'As a district nurse, I have seen more and more care given by HCAs. When I go in I have to spend a lot of time sorting out problems that have been missed or caused by lack of knowledge. I have come across several cases of wrongly used equipment, and poor clinical judgement.'

'Health care assistants have been trained to do tasks previously undertaken by RGNs e.g. giving insulin, enemas, compression bandaging and routine catheterisation. Health needs assessments are completed by team members without DN training.'

'I believe skill mix is reaching levels of high risk.'

'For the last 5 years we knew this was coming, the aim is 40% trained & 60% untrained within our PCT.'

'There is a real focus on assistant practitioners and de-skilling the qualified practitioners. Who is going to take accountability?'

Impact on patients/ carers

'Having recently received specialist nursing care in my home from an excellent team, the community IV therapy team and my GP, my strong belief in the need for specific and relevant education and training has been reinforced.'

'As a carer I really valued the time the DN came to care for my relative as I felt I could ask questions that I felt they were able to answer with great depth of knowledge and insight and also that they were assessing my relative holistically rather than providing a care task only.'

'I've recently had three months District Nursing care & valued the skills of the most experienced nurses. The limitations of the less experienced were apparent in that they can do a task to a set written plan but not adapt to changes as they arise or respond to wider needs.'

'My partner's Grandfather is ill and in and out of hospital. When out of hospital he is seen by carers instead of very expensive nurses. I feel that if he were seen by nurses on a more regular basis he would not have such difficulties when at home.'

## Theme

## Comments from supporters of RNRS

Impact on patients/ carers (cont'd)

'It is not the shortage of home visits, these are kept up well by them literally running in and out. Their actual nursing skills most times non existent need much improvement. The nurses are not knowledgeable about their function or the patients condition and their advice is negligible. Perhaps the whole idea of being sued may have something to do with it, but I feel if a nurse is well trained she should have the courage of her convictions.'

'As a patient who has had experience of being cared for recently, I would like to see a real attempt to bring basic nursing care back into being valued.'

'Having been a user I have seen at first hand that due to insufficiently trained staff and inappropriate staff being sent and designated to care at home when discharged from hospital lead to a worsening and a readmission.'

'As a carer for my husband, stroke and fracture skull ... it is imperative that the 'carers' no matter at what level they have training to cope with the needs of the patient. It is often the small things which make all the difference to care e.g. knowing the importance of ensuring the client actually has a drink and not just leaving it and hoping they will take a drink, also to realise the stroke patient tend to think slower and so a bit of patience means a lot with instructions, and so get results. Have most nurses and or carers forgotten or not learned how to read body language as it can tell a lot.'

'It appears there are suitably qualified nurses in GP surgeries but my Father lives in another area and has had dressings completed by HCA staff on occasions.'

'I had excellent help and care from the local district nursing team who helped care for my terminally ill mother. The skills used were of the highest standard, the empathy and understanding given to the family and my mother was second to none from professional trained staff. Unfortunately this could not be said of the untrained carers who attended one day. E.g. turning up to bed bath with large rings, long mails. Whilst working with the manager who was not a nurse, insisted on lying a dyspnoeic, oxygen dependent patient flat to change sheets even though with help of me alone could get out of bed. When I stopped them lying her down and explained why she had become agitated and could not breathe the manager still insisted that this was the only way to change a bottom sheet, if I wished to get her on and off the bed I must do it myself as there were not covered to move her without a lift. Trained staff had helped me on several other occasions without any problem. Fortunately for my mother she no longer required care from the untrained staff as she died later that evening not really recovering from the episode of being laid flat.'

Impact on workforce

'50 nurses have left my PCT since April and the teams are always on red alert which is working to unsafe practice levels.'

'There has recently been errors happening which may be associated with low numbers of nurses working in the community and of these how many have undertaken a SPQ programme.'

'In sheer desperation, many, including myself, have left to find alternative employment.'

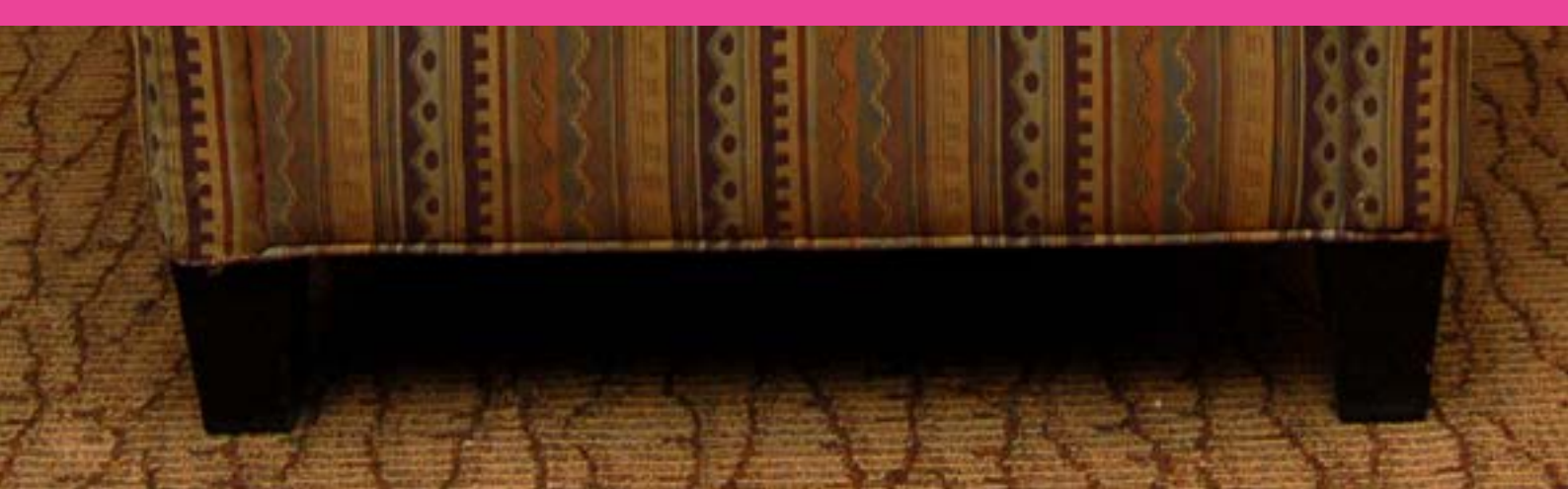
'Removing the district nurse from the team to case manage patients has had a huge impact, resulting in a lack of leadership and a loss of morale.'

'We are now working outside the hours we signed up for, we have less staff and morale is at its lowest ebb. We are about to lose two highly skilled DNs to early retirement because of these enforced changes and they will not be replaced with the same skill mix and one may possibly not be replaced at all. This is having a detrimental effect on staff as we are now unsure of our future. Many nurses believe the district nursing service is being dismantled to be sold off to the lowest bidder.'





**Appendix B – Being at Home Checklist**





## Being at Home Checklist : Top Tips From Our Queen's Nurses

Patients have a key role to play in their care. So here are some top tips from our Queen's Nurses, and from the QNI, about being a patient at home.

### About You

- Let your nurse know about your needs and preferences** - this can be done through the initial assessment once you have arrived home or via on-going feedback during your treatment. You should mention anything that is important to you, even if you think it will not be important to anyone else.
  
- Explain your support networks** - understanding your support networks is vital to delivering good care. So remember to let your nurse know who is helping you out while you are receiving care at home and if there are changes in the assistance you receive from your support networks. If you have no-one to support you, your nurse will want to know this too.
  
- Familiarise yourself with your care plan** - your care plan helps you manage your day-to-day health requirements. It includes things like treatments, medicines, eating plan and emergency numbers. If you don't understand any of the terms used in the plan, ask your nurse to explain them.

### Your Medicines

- Take them as prescribed** - do not change dosages or stop taking any medications without checking with your GP or nurse first.
  
- Look after them carefully** - make sure you keep medicines in their original packets (unless you are using a dosage tray - see below) to avoid confusion; keep all your medicines out of reach of children who may visit you; some medicines need to be stored in a fridge – your nurse will tell you if this is the case.
  
- Get help with dosage** - if you have trouble remembering which tablet to take when, ask your nurse for advice about a dosage tray, which is a special piece of equipment that can help you to put out your medicines day by day, to help you take them at the right time.
  
- Look out for side-effects** - tell your nurse or GP if you think you are getting side-effects from your medicines.
  
- Ask about nurse prescribing** - you may find that your nurse is able to prescribe medicines for you. Your pharmacists will treat the nurse's prescription exactly like a doctor's prescription.



## Who's who

- Be aware of who is coming to visit** - anyone who comes into your home to care for you should have an identity badge and will be happy to tell you their name, who they work for and what their job title is. Job titles do vary a lot, but you can always ask them to explain whether they are, for example, a registered nurse, a healthcare assistant or another kind of carer.
- Ask for your named nurse** - you will have a named nurse who is a registered nurse and they are responsible for the co-ordination of your care; though other members of their team may come to treat you from time to time. Your care plan will include their contact details. If your named nurse is not on duty you can discuss any issues with a member of your community nursing team.
- Know who to call in an emergency** - irrespective of your situation, it's important to be prepared in the unlikely event of an emergency. Contact details will be in your care plan.

## Safe and Secure

- Take steps to feel safer at home** - you could purchase a key safe to store keys on the exterior of your home for convenience or emergency access, if you are unable to come to the door. Never leave the door open or 'on the latch' for the nurse or other carer.
- Ensure safety within the home** - your nurse may give advice about hazards in your home, such as rugs you might trip on, or poor lighting. This is to help ensure your safety and comfort while you are getting better.
- Wash your hands** - don't be afraid to ask or remind your nurse about hand hygiene. Your nurse will either use your facilities to wash their hands with soap and water or may use an alcohol based disinfectant hand rub.
- Observe good hygiene** - your nurse may use sterile towels laid on your furniture as they work. They may also put a clean towel on the floor if they need to kneel to treat you. This is normal hygiene practice whilst giving nursing care, and doesn't mean they think your home is dirty.

## Be Involved

- Ask questions** - you should never be afraid to ask questions about your treatment, it will help you to be involved in your care.
- Seek information** - your nurse will have access to a range of information products that can help you understand your condition, treatments, medicines and other support services. You should say how you prefer to receive information – e.g. in a leaflet, verbally or on the internet.
- Sharing decisions** - tell your nurse that you want to work with them to make choices about your treatment and care.

## Share Your Experience

- Know you have a right to complain** - if you experience problems with your treatment or care, talk to your named nurse to seek a resolution. If this is not possible, or does not resolve the problem, contact the service manager or your local patient advice and liaison team.
- If you experience excellent care, say so** - there are many ways to compliment your nurse/s if they have exceeded your expectations. It could be a kind word or, a more formal letter.
- Nominate your nurse for a Queen's Nurse title** - if you know a community nurse who you believe is a good role model and demonstrates high quality care encourage them to apply for a Queen's Nurse.





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