

## Department of Health

### Final report on the review of the Department of Health Dignity in Care Campaign

November 2009



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# 1. Executive Summary

The Dignity in Care Campaign was launched by the Department of Health (DH) in November 2006. It aims to address the lack of dignity in health and social care services by stimulating national debate around dignity in care and inspiring people to take action. The Campaign has included a range of activities to promote dignity and respect for patients using care services. In particular, it has adopted a Dignity Challenge that lays out the national expectations of what constitutes a service that respects dignity. This focuses on ten different aspects – ranging from the need to treat each person as an individual to alleviating people's loneliness - of dignity. The Campaign has created a network of more than 10,000 'Dignity Champions' to work locally.

Opinion Leader was commissioned by the DH to carry out a review of the Campaign. The task was to determine the progress achieved – both successes and areas for improvement – and outline recommendations for the future.

As part of the overall assessment of the Campaign, the DH commissioned the NHS Information Centre for Health and Social Care (NHSIC) to assess Dignity Metrics to quantify changes in dignity and patient experience over the last three years. The full Dignity Metrics report is available via the link below as a standalone document as part of the recently developed National Adult Social Care Intelligence Service (NASCIS) Library.

NASCIS (<http://nascis.ic.nhs.uk>) is owned and delivered by the NHS Information Centre for health and social care (NHSIC), and is central to the NHSIC's strategic direction on adult social care. Please note that the full Dignity Metrics report will be available in the NASCIS library, under 'Useful documents'.

The DH also carried out an Input Assessment of the Campaign, which outlined the success of various activities and resources – such as the website, regional events and guidance - used to support the Campaign.

Opinion Leader began the research programme in mid-June 2009 and finished in late September 2009. During this period, Opinion Leader undertook a range of research activities to address the objectives of the review. The main findings of the review are:

## Successes of the Campaign

- A large number and different types of Dignity Champions have signed up to the Campaign

- The Campaign has managed to attract new Dignity Champions while sustaining the input of those who joined earlier
- The expectations of the majority of those that have taken part in the Campaign have been met
- The Campaign has empowered many, and has provided immense pride and satisfaction to those providing services and care. It has also created leaders and role models, whose actions relating to the Campaign may inspire others
- The resources and tools of the Campaign have proved useful in giving information/guidance as well as motivating and inspiring those involved
- The case studies collated as part of the Review exemplify an array of good practice across health and social care that can be communicated widely
- Quantitative analysis of a number of metrics relating specifically to dignity issues show steady improvement over the last three years. This is most notable in the Privacy & Dignity, Autonomy & Choice and Meals & Mealtimes findings from the National Minimum Standards (NMS) for older people's homes. Similar, gradual improvements can be seen in a number of dignity related questions from the Adult Inpatient surveys across the same period

#### **Areas for Improvement**

- Lack of time has impeded many Dignity Champions in devoting time to their role
- There is variance in the frequency and quality of patient feedback being collected to measure impact of different initiatives by Dignity Champions
- Many of the initiatives by Dignity Champions have helped services to achieve minimum standards rather than to go beyond them
- Influencing senior leaders across health and social care has been a challenge for most Dignity Champions
- Quantitative analysis of dignity related metrics over the last three years shows that the mixed sex wards detrimentally affects patient experience and feedback. NHS trusts can still progress in relation to improving privacy and confidentiality practices and standards

#### **Conclusions on impact**

In relation to the individual objectives of the Campaign, the review has found that:

- Dignity in care related issues are of a higher priority than in the past. The number of Dignity Champions that have joined and the local and national networks that have been created for them have helped in this regard
- The Campaign provided Dignity Champions with freedom. As a result, a lot of different local initiatives have been developed
- A common understanding of what constitutes patient dignity has been aided via consistent Campaign messages and communications

- Many Regional Dignity Leads and Dignity Champions think that without the Campaign a lot of progress would not have been achieved. A number of the service users who were interviewed as part of the case study visits had a similar view

#### **Key recommendations**

The review proposes a number of actions for the consideration of the Department of Health and others leading the Campaign. These include:

- Clearer guidance on measuring and tracking patient experience would help those on the ground to effectively quantify and track impact
- Despite linkages between dignity and other DH policy work streams being made, this is an area that requires more focus and time
- In order to sustain and develop the Campaign in the future, regional and local stakeholders need to take ownership
- Those on the ground are seeking clarity from the Department of Health on the future of the Campaign
- Successes of the Campaign need to be more proactively communicated to the public. The approaching 3<sup>rd</sup> anniversary would be an ideal time to action this
- Recognising and emphasising the importance of staff being treated with dignity and respect by their employers

## 2. Introduction to the Dignity in Care Campaign and this Review

Launched by the Department of Health (DH) in November 2006, the 'Dignity in Care Campaign' aims to end tolerance of care services that do not respect people's dignity by stimulating national debate around dignity in care and inspiring people to take action. The objectives of the campaign are to:

- Deliver a public/staff facing 'Dignity in Care Campaign' aimed at:
  - Raising awareness and stimulating a national debate around Dignity in Care
  - Inspiring and equipping local people to take action
  - Rewarding and recognising those who make a difference
- Create a common understanding of what dignified health and social care services look like
- Communicate dignity as a priority through consistent messages. And to include it in key levers and guidance produced by DH and other stakeholder organisations

Since it began, the Campaign has included a range of activities to promote dignity and respect for patients using care services. In particular it has created a network of more than 10,000 Dignity Champions to work locally, inspiring and encouraging others to make dignity and respect a priority for care services. The Campaign has also worked to raise awareness via a variety of methods: pod casts, an online website, partnership with the Social Care Institute for Excellence (SCIE) to create an online practice guide, awards, conferences, a 'Dignity Tour', and so on.

The following definition of dignity has been developed by the DH and the SCIE:

### **What is dignity?**

Dignity consists of many overlapping aspects, involving respect, privacy, autonomy and self-worth. The provisional meaning of dignity used for this guide is based on a standard dictionary definition:

a state, quality or manner worthy of esteem or respect; and (by extension) self-respect. Dignity in care, therefore, means the kind of care, in any setting, which supports and promotes, and does not undermine, a person's self-respect regardless of any difference.

While 'dignity' may be difficult to define, what is clear is that people know when they have not been treated with dignity and respect. Helping to put that right is the purpose of this guide.

*Box 1: What is dignity? (taken from the Social Care Institute for Excellence, Dignity in Care Practice Guide )*

In early 2009, Opinion Leader and the NHS Information Centre for health and social care were commissioned by the DH to carry out a review of the Campaign. Specifically, the key objectives were to

determine:

- How effective has the Campaign been in terms of changing culture and practice and improving the way people experience dignity in care?
- What is driving Dignity Champions to tackle dignity locally and how effective have they been?
- What is the view of the Campaign amongst key stakeholders? – i.e. Regional Dignity Leads, Dignity Champions, senior leaders in health and social care and other stakeholders?
- What gaps and future opportunities are there for the Campaign?
- Evaluate and analyse any existing metric data collated by agencies or governmental departments pertaining to dignity
- Provide quantitative analysis of pre- & post- 2006 in measuring progress in the Dignity area

Upon commissioning, the Department of Health recognised that determining and differentiating the unique impact of the Dignity in Care Campaign on promoting good practice across health and social care from the host of other national and local initiatives would be impossible.<sup>1</sup> DH has implemented a number of policy interventions aimed at improving people's experiences of care since 2006. These include:

- A number of high profile strategies which promote dignity and respect including "The National Dementia Strategy" (2009); "End of Life Care Strategy" (2008); "The Carers Strategy" (2008)
- Inclusion of dignity in the National dataset and in the NHS Operating Framework (2007)
- The focus on quality and patient experience through the NHS Next Stage Review (2008)
- The new NHS Constitution (2009) which includes a right to dignity and respect

The regulatory background has also changed, with the Health and Social Care Act (2008) making independent sector care homes directly subject to the Human Rights Act and the creation of the Care Quality Commission (CQC) in April 2009 harmonising the regulatory framework and inspections. Therefore, we proposed and carried out a host of research techniques to identify the successes and areas for improvement of the Campaign. In doing so, we are confident that the effectiveness of the Campaign can be assessed in a more robust manner.

Similarly, as part of the overall assessment of the Campaign, the NHS Information Centre for health and social care was commissioned to identify and then assess Dignity Metrics used at a national and local level to measure any changes in dignity and patient experience in the last three years from both a health and social care perspective. An internal Input Assessment of the Campaign was also commissioned. Both of these analyses provide information and conclusions. The work on the Dignity Metrics provides a valuable quantitative view of dignity in care from a range of health and social carer

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<sup>1</sup> Furthermore, quantifying and tracking something as subjective and nebulous as dignity is not an easy task.

sources both historically and currently. Relevant findings from these analyses are interspersed within the body of this report as well.

The project began in mid-June 2009 and finished in late September 2009. During this period, Opinion Leader undertook a range of research activities – including a literature review, an online survey with senior leaders in health and social care and telephone interviews with Regional Dignity leads - the results of which culminate in this final report. The Review provided a unique opportunity to listen to the views of those directly and indirectly involved in delivering this important initiative. The overarching objective underpinning our approach was to involve and engage as many of these individuals as possible. This was achieved by providing the relevant respondents with a range of techniques to get their views across. It was also imperative that:

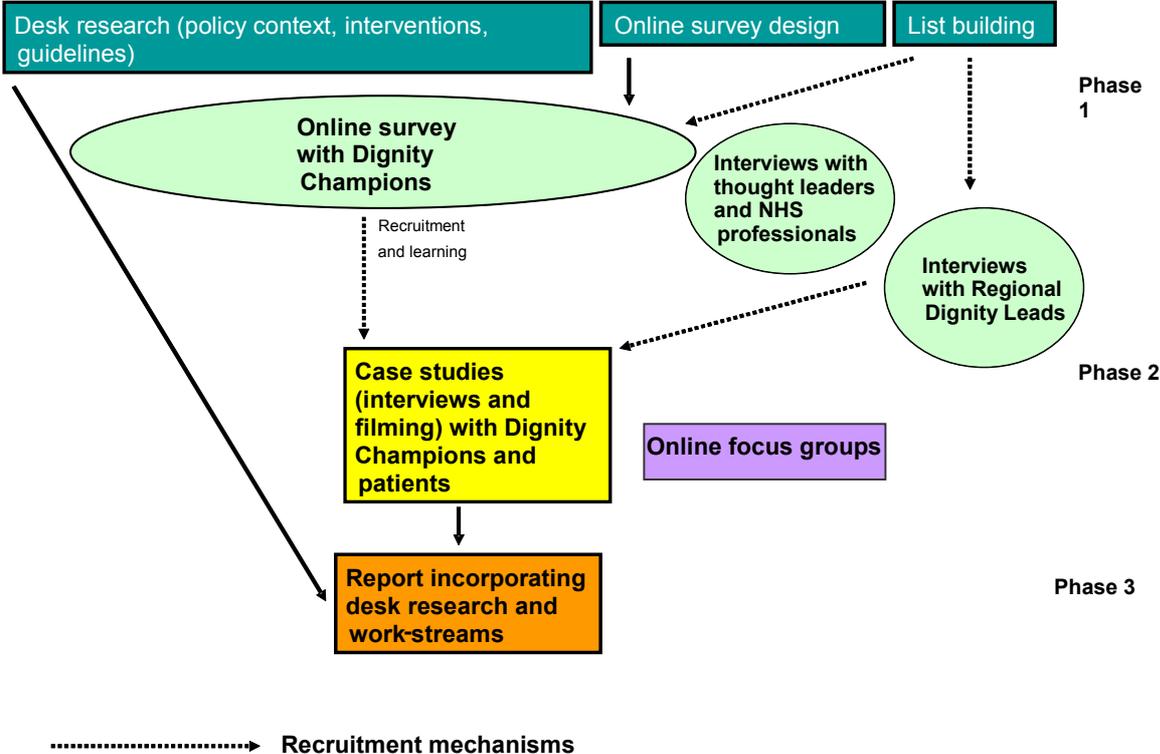
- The process was robust and transparent to ensure that it had credibility
- All research materials were clear and concise
- A mix of primary and secondary sources of information were used

### 3. Methodology

As mentioned in the introduction, the review employed a number of research techniques – including qualitative and quantitative methods - and tools. The main reasons for using a multifaceted approach was, firstly, to address all of the DH objectives, and secondly, to make sure that all relevant stakeholders across the nine government regions had a range of methods through which to submit their views. As a result of this user-focused approach, a total of approximately 1,400 individuals were engaged as part of this Review.

Figure 1, below, depicts our phased method for carrying out the review.

Figure 1:



#### 3.1 Description of research phases

##### Phase 1

After an initial scoping meeting at which the project background and desired objectives were discussed in more detail, we carried out a **literature review** to gain insight into the issue of dignity in care and identify and summarise the key reports relating to:

- The key background policy drivers from which the Dignity in Care Campaign emerged and within which it is currently operating. This covered national strategies, guidance programmes and initiatives
- National studies to guide and evaluate the Dignity in Care Campaign
- Local action by Strategic Health Authorities (SHA), Primary Care Trusts (PCT) and local councils to develop and evaluate activity relating to the Dignity in Care Campaign in the NHS and social care

A detailed search of the relevant national and local public sector websites and health and social care journal sites was carried out to assess policy thinking behind the campaign and progress in developing and evaluating the campaign on a local basis. The key sources examined included, among others:

- Department of Health and Social Care Institute for Excellence (SCIE) websites and reports
- Healthcare Commission and Care Quality Commission websites
- Social care databases – e.g. Intute, Social services abstracts, social care online
- Pubmed database
- Picker Institute
- Royal College of Nursing
- Community care journals/ Age and Ageing/Quality in Ageing
- Charity web sites e.g. Age Concern/Help the Aged

The output from this activity is a stand-alone compendium of the reviewed sources. Each study and/or report is presented and analysed individually: short annotated notes on the format and content are used.

The second strand of the first phase was a series of five interviews with **Key Thought leaders** – senior individuals who have provided input into the Campaign at the national level - to ascertain views on their:

- Awareness of the Campaign and its objectives
- Perceptions of the Campaign (impact and progress achieved since implementation)
- Priorities for Campaign improvement

This interaction assisted us in benchmarking views and perception at the national level, and then comparing these with the views of those from the regions. The other benefit of targeting this cohort was that we ascertained the awareness and perception of those not directly involved in the Campaign.

## Phase 2

This phase of the review commenced with the development and facilitation of two surveys – online and postal - aimed at **Dignity Champions** and **senior leaders** in health and social care. The surveys were designed to collate awareness, perception, perceived impact and views on future direction of the Dignity in Care Campaign. The surveys targeted those who had been directly or indirectly involved in the

Campaign. The survey insights were used to inform subsequent qualitative engagement with (and recruitment of) **Regional Dignity Leads** and Dignity Champions in each of the regions.

Interviews with Regional Dignity Leads also formed part of the second phase. These structured telephone discussions were designed to provide insights into the impact of the Campaign in each of the regions. They were also helpful in identifying contacts for good practice case studies. The development of such stories was a key deliverable for the project. To fulfil this requirement, phase two was also used to contact Dignity Champions across the regions to gather more specific information on their initiatives. Most of this interaction took place on the telephone. However, we also conducted a series of site visits to the concerned case study localities and conducted interviews with those involved – Dignity Champions, other staff, patients and the public - in delivering them. Five of these visits were filmed for the purpose of providing footage for a promotional DVD showcasing the local initiatives Dignity Champions have been involved in. A selection of case studies has also been used in the body of this report to complement our analysis, where relevant and appropriate.

**Phase 3**

The final phase of the project concerned the dissemination and discussion of some of the key findings of the research with Dignity Champions via 3 online focus groups. This acted as a nice feedback loop, and also helped us in gauging reactions to our findings and recommendations. The last phase also consisted of comprehensive analysis and synthesis of all the data generated from the various research mediums into a coherent report that tackles the key objectives and outlines recommendations for the Campaign in the near future.

The table below outlines the number of people engaged via the different research methods used as part of the review.

**Table 1:**

Research technique	Total number involved in review
Interviews with Senior Thought Leaders	5
Interviews with Regional Dignity Leads	8
Online survey with Leaders in health and social care	220
Online and postal survey with Dignity Champions	1,147
Online focus groups with Dignity Champions	25
<b>Total</b>	<b>1405</b>

## 4. Main findings of the Review

This section of the report outlines the key findings emanating from the analysis of the different research activities that were undertaken. Instead of presenting chronological findings from each of the research strands individually, we outline and discuss the key themes that have emerged and intersperse specific findings from the methods accordingly.

Paraphrased comments from those taking part in the survey, interviews, site visits and online focus groups have been included where appropriate. It should be noted that these are not always verbatim quotes as the format of the interaction did not always allow for audio recording.

### 4.1 Differences in progress across different regions

The aim of the Review was to identify the progress achieved by the Campaign against its overarching objectives. However, the DH made it clear that the onus was not on creating a league table of government regions according to what each had attained. Instead, the Review was to pull out the key successes and areas for improvement in a general manner. Throughout this report we have drawn out noticeable conclusions (where they exist) by theme and respondent type (i.e. Dignity Champions as opposed to Regional Dignity Leads) and the mediums used as part of our research.<sup>2</sup> As a result, this Review and its findings apply to all the regions and should be perceived in that manner.

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<sup>2</sup> Where differences are not highlighted this is because the views expressed are largely universal.

## 5. Awareness of the Campaign

### Introduction

As outlined in the introduction, one of the key aims of the Campaign was to raise awareness and stimulate a national debate around dignity in care. Since it launched, the Department of Health - in partnership with a range of stakeholders - has taken concerted action to promote dignity and respect for people using care services via the Campaign. In order to ascertain the effects of such efforts, we focused on understanding the awareness of those directly or indirectly involved in the Campaign. This was undertaken not only by asking specific questions in the surveys but also by asking questions on the respondents' familiarity with the aims and objectives of the Campaign and what it entails.

This section presents the analysis of the feedback received on this aspect of the Campaign.

Awareness of the Campaign amongst those who took part in the research was quite high. Obviously, this was expected to be the case for those who have been directly involved i.e. Key Thought Leaders, Regional Dignity Leads and Dignity Champions. However, in terms of those not involved (such as Leaders working in health and social care), 81% (179) of the total 220 survey respondents were aware of the Dignity in Care Campaign.

Table 2 shows the percentage of Leaders in health and social respondents that were aware of the Campaign across the government regions. It also outlines the total pool of respondents in each region.

**Table 2:**

Region	Total pool of respondents	Aware of the Campaign
North East	30	83%
North West	31	74%
Yorkshire & Humber	30	80%
West Midlands	14	100%
East Midlands	7	86%
East of England	27	78%
London	23	65%
South West	15	87%
South Central	12	92%
South East Coast	24	88%
Not stated	7	75%
<b>Total</b>	<b>220</b>	<b>81%</b>

Those working as Chief Executives had the highest awareness (29 out of 33 respondents). Those working in Commissioning had the lowest (21 out of 32 respondents).

Out of the 179 who were aware about the Campaign, only 51% (91) were aware of the Regional Dignity Leads and Dignity Champions working in their area. This is interesting because it shows that although there is high awareness of the overall Campaign across the regions among Leaders in health and social care, the majority of these individuals are not aware of the two most important deliverers in the Campaign (Regional Dignity Leads and Dignity Champions). However, the pool of respondents is too small to make such comparisons robustly.

The interviews with the Key Thought Leaders and Regional Dignity Leads revealed that many felt passionate about the Campaign and the concept of dignity generally. Most had a professional background in developing patient dignity and respect.

*“We are all coming from the same direction as the Campaign”.*

**Key Thought Leader**

There was a consensus that the Campaign’s main focus was on increasing awareness and in doing so, making those concerned about embedding a greater focus on dignity, act. The 10 point Dignity Challenge was commonly mentioned as integral to the Campaign. There was good knowledge that the Campaign was approaching its third anniversary.

A number of individuals were able to recount the policy journey that resulted in the Campaign in 2006. Several respondents believed that the initial focus of the Campaign was solely on tackling lack of dignity, respect and abuse for older people in care. It was perceived that the Campaign evolved to include other types of service users across health and social care boundaries.

*“It soon became apparent that dignity is something that underpins {everything} about how a patient is looked after. The Campaign had to embrace this and as a result took on a much bigger challenge”.*

**Regional Dignity Lead**

Our literature review also found that the reviewed sources agreed on the central importance of dignity in care and the development of the Campaign across the country as a vital step to achieving this objective. Those aware of the Campaign consider it to be integral to the wider quality and patient safety agenda.

## 6. Role and experiences of Regional Dignity Leads and Dignity Champions

### Introduction

The respective roles of Regional Dignity Leads and Dignity Champions are a crucial element of the Campaign and its impact. In the Dignity in Care Regional Delivery Plan (Department of Health, 2006/7-2009/10), it is stated that Regional Dignity Leads are to act as a “regional resource accountable to the respective Deputy Regional Director for delivering regional activity.” Specifically, they have the responsibility for:

- Improving awareness of the Campaign, and in doing so increasing the number of individuals signing up as Dignity Champions
- Supporting those who sign up as Dignity Champions to be effective in their roles
- Reporting progress made on the key themes identified for their region
- Embedding dignity in all local implementation activity across their region

Dignity Champions are individuals who have signed up to the Dignity in Care Campaign because they are willing to improve services through initiatives that are more compassionate, person-centered and efficient, and are willing to try to do something to achieve this.

As part of the Review, it was important to determine how those involved in delivering the two key roles of the Campaign have found their experience. Views in this regard were collected through a combination of quantitative – online and postal surveys – and qualitative – telephone interviews, site visits and online focus groups – techniques.

This section presents the analysis of the feedback received on this aspect of the Campaign.

### 6.1 Reasons for joining the Campaign and overall experience

#### Regional Dignity Leads

The majority of Regional Dignity Leads became aware of and later joined the Campaign due to their professional experience. Several were working in related policy areas that incorporated elements of improving patient dignity and respect.

*“I was the local lead for the Older People in Care Strategy, which patient dignity and respect formed a large part of, and became aware of the Campaign through that involvement.”*

**Regional Dignity Lead**

A couple of Regional Dignity Leads took up the role because they were either asked to or were told that a position had become available. Regardless of their respective reasons for joining, it was evident through the interaction with the Regional Dignity Leads that they felt passionate about the values and aims of the Campaign. This motivation and appetite “to make a difference” seems to have proved beneficial to the individuals working as Regional Dignity Leads. Indeed, all of them stated that their overall experiences of the Campaign were positive.

*“The Campaign, specifically its high profile, has helped me to work on something which I believe underpins everything good and bad about the National Health Services and social care in England. It has enabled me to knock on doors and get the message across. Just being able to do that is gratifying...there is a long way to go but at least we have started the journey.”*

**Regional Dignity Lead**

When asked whether their expectations of the Campaign and their role had been met after they had actually taken up their respective positions, most Regional Dignity Leads felt that they did not have any initial expectations. Those who did have expectations felt that most of these were around their key role in encouraging front-line staff, patients and members of the public to become Dignity Champions.

*“When I first joined, it was pretty clear that the onus was on getting Dignity Champions signed up. There did not seem to be much focus on doing anything else.”*

**Regional Dignity Lead**

There was a consensus that the strategic need to influence senior managers, Chief Executives, PCT Board members as part of their roles came after this.

*“When we started getting the phenomenal response from the ground, it was obvious that we had to make efforts on senior professionals to recognise the changes that were being made or needed to be made.”*

**Regional Dignity Lead**

From the interaction with Regional Dignity Leads, it is apparent that at the beginning of the Campaign, they felt as if they were involved largely in a logistical capacity (i.e. increasing the number of Dignity Champions). More recently they feel that they have provided a regional strategic steer to the Campaign (i.e. via creating networks of Dignity Champions and/or embedding dignity in care across other SHA, PCT or local authority programmes, strategies and plans).

## Dignity Champions

In the online survey, Dignity Champions were asked about the reason they decided to participate in the Campaign. The vast majority (89% of 1,147 pool of respondents) stated that this was due to their professional experience. It was very evident from the interaction with the Dignity Champions that most of them got involved because they believed care services and practices could be improved. A number of Dignity Champions also became involved as a result of the efforts of colleagues who had become Dignity Champions.

*“My line manager was a Dignity Champion. Seeing their passions for the change motivated me to become one as well.”*

**Dignity Champion**

Several patients and members of the public were also engaged in the Review. The majority of these individuals had taken up the Dignity Champion role due to a negative personal experience of receiving care. A few were carers and family members of patients who had received sub-standard care.

*“Seeing my mother receiving uncompassionate care really hit me hard. I wanted to do something about it and sought advice from a friend who worked in the NHS. She told me about the Dignity in Care Campaign. As soon as I read up on it, I knew that I could join to influence the local hospital to take notice of how some patients were being treated.”*

**Dignity Champion**

The survey also included a question on the how long the respondent had been a Dignity Champion for. The pie chart, overleaf, shows the percentage of responses according to each of the time limits.

If the same question is analysed against the role/setting of Dignity Champions then it is apparent that 45% of the health and social care champions have been in post for less than six months. Those from the voluntary sector were likely to have been in post for the longest duration (26%).

Dignity Champions were also asked about their expectations at joining; 25% of the 1,147 total respondents felt it was to 'generally promote the level of care and support available for patients'. Surprisingly, only 5% stated that they wanted 'to ensure patients are treated with respect'. In total, 32 different kinds of expectations were outlined; the breakdown of the remaining answers was thinly spread across these.

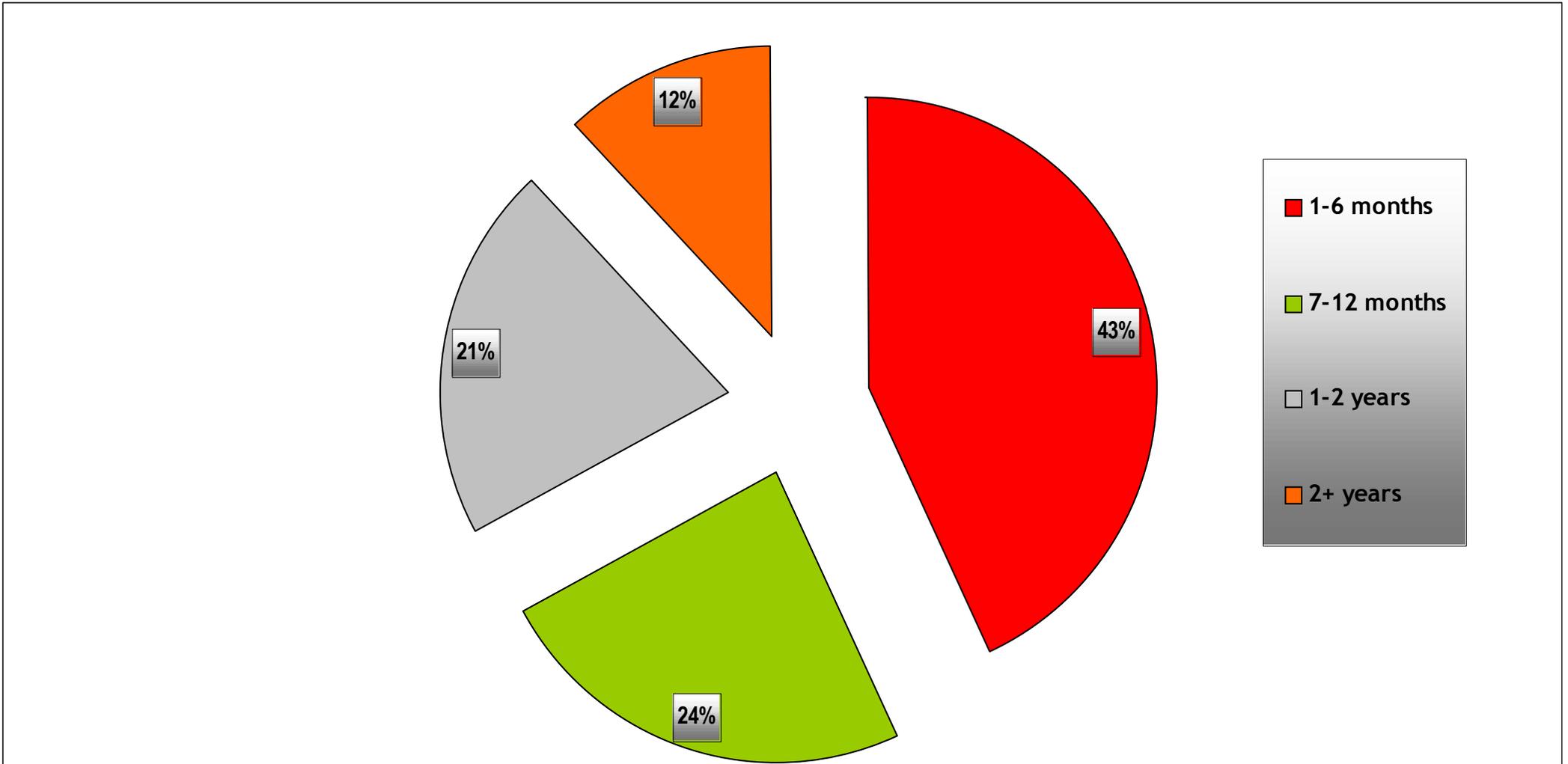
## 6.2 Regional Dignity Leads and their support of Dignity Champions

On the whole, Regional Dignity Leads have provided support and advice to Dignity Champions, when the latter has asked for it. Indeed, the analysis suggests that the large majority of Dignity Champions have been allowed to "get on with it". However, there are some regions where a considerable amount of time, resources and effort has been spent by the Regional Dignity Leads on organising conferences and networks for Dignity Champions. Recently, a couple of regions have jointly arranged such events.

The regions in which this has not happened seem to be recognizing the importance of such interventions; a couple of Regional Dignity Leads mentioned upcoming events and/or plans for increased good practice sharing between their respective Dignity Champions.

In terms of explaining the variance in the approaches Regional Dignity Leads have taken to work with Dignity Champions, it is noticeable that there is a common perception that the Campaign intended to deliver according to local and specific contexts and needs. Moreover, there was a feeling amongst some of the Regional Dignity Leads that proactively supporting Dignity Champions with their queries would have impeded their ability to influence change at a more strategic level.

**Graph 1: Length of time in role as a Dignity Champion**



## 7. Key successes of the Campaign

### Introduction

The Dignity in Care Campaign is approaching its third anniversary. Due to a number of reasons it is important to identify and discuss the resulting impact of the Campaign. Firstly, time and effort have been invested in this initiative by the Department of Health at the centre and the numerous partners and stakeholders across the regions. Secondly, and perhaps more crucially, the Campaign encapsulates a vital concept that underpins patient experience across health and social care.

From the surveys, telephone interviews, case study development and online focus groups, we have developed a large pool of information on the impact of the Campaign. From its analysis, a number of key successes have emerged; these need to be recognised, further embedded and celebrated. This section of the review provides commentary on these successes. It specifically, examines the positive perceptions of the Campaign and describes some of the themes that have been uncovered. The focus is on identifying and describing the nature of the improvement, and presenting the impact/outcome for the dignity of the patient.

This section presents the analysis of the feedback received on the key successes of the Campaign.

### 7.1 Number and type of Dignity Champions

The Dignity in Care Campaign has been rolled out across the regions over the past three years. As mentioned above, the work of the Dignity Champions is integral to its success as these individuals constitute the 'agents' through which change is being achieved.

The Input Assessment (DH, 2009) states that over 10,000 Dignity Champions have signed on to the Campaign since it launched in 2006. This is a very large number of people who have taken the initiative to participate and in so doing strive for positive change. It can be determined from the list of Dignity Champions held by the Department of Health that a range of professionals have been attracted. In addition, a number of patients and members of the public have also become involved. From our analysis, it is evident that the following types of individuals have become Dignity Champions across the nine government regions:

- Chief Executives and Board level representatives
- Senior Managers across health and social care
- Frontline health and social care employees

- Local Involvement Network and other patient advocacy representatives
- Member of Parliaments and local authority councillors
- Members/representatives of voluntary sector and advocacy organisations
- Patients, family members, carers and the public

The table below depicts the type of Dignity Champions who took part in our survey. It is worth mentioning that while the survey was live for only four weeks, a total of 1,147 responses were generated. This amount of data provides adequate breadth and depth.

**Table 3:**

Region	Role/setting of Dignity Champion	Health Care/Social Care	MP/Councillor	Voluntary/Advocacy Organisation	Member of Public	Local Involvement Network	Other
East of England		100	1	5	3	1	7
East Midlands		101	1	0	3	1	4
West Midlands		105	1	4	5	1	14
London		76	0	8	1	0	8
North East		92	2	3	1	2	3
North West		141	1	9	5	1	14
South West		79	1	8	2	1	4
South Central		39	0	1	1	0	5
South East Coast		71	0	3	1	0	3
Yorkshire & Humber		119	1	13	4	1	7
Not stated		36	1	4	2	0	16
<b>Total</b>		<b>959</b>	<b>9</b>	<b>58</b>	<b>28</b>	<b>8</b>	<b>85</b>

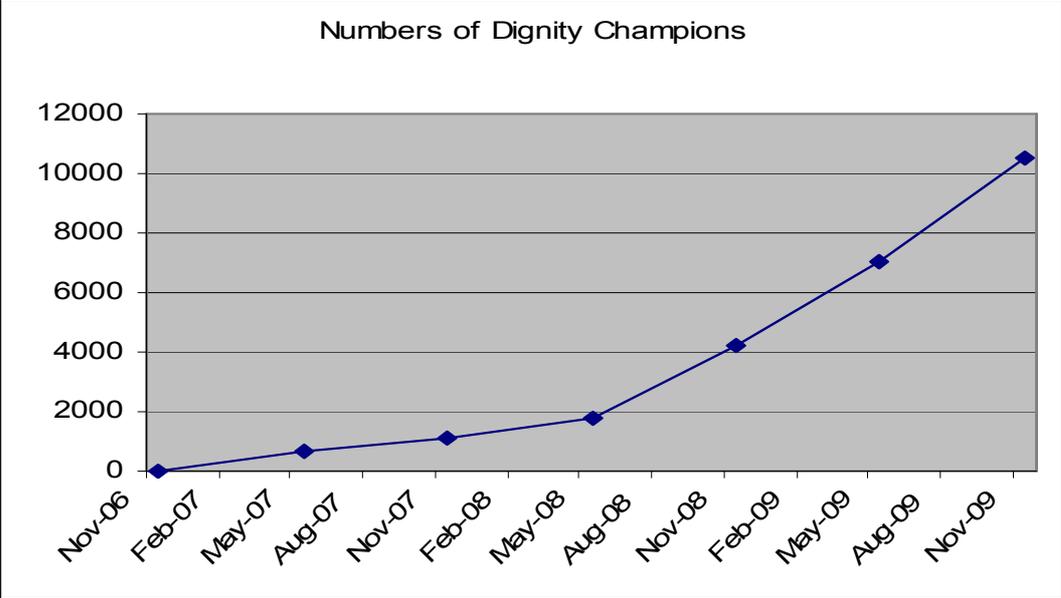
## 7.2 Length of time as a Dignity Champion

As already mentioned, another positive emerging from our analysis is that a large number of Dignity Champions who submitted a survey response have been part of the Campaign for a considerable amount of time. Indeed, 57% had been a Dignity Champion for longer than six months; 43% had joined in the last six months. These figures suggest that the Campaign has succeeded in achieving continuity for those that joined some time ago as well as attracting others more recently. This continuity bodes well for the Campaign as it shows that these Dignity Champions have felt it worthwhile to sustain their involvement.

Obviously, our interpretation assumes that the concerned Dignity Champion is actually delivering change by being part. It is worth noting that the Department of Health has been maintaining the list to account for Dignity Champions joining and/or leaving.

The graph below is taken from the Input Assessment of the Dignity in Care Campaign (DH, 2009) and depicts the increase in the number of Dignity Champions since the Campaign launched in November 2006.

**Figure 2:**



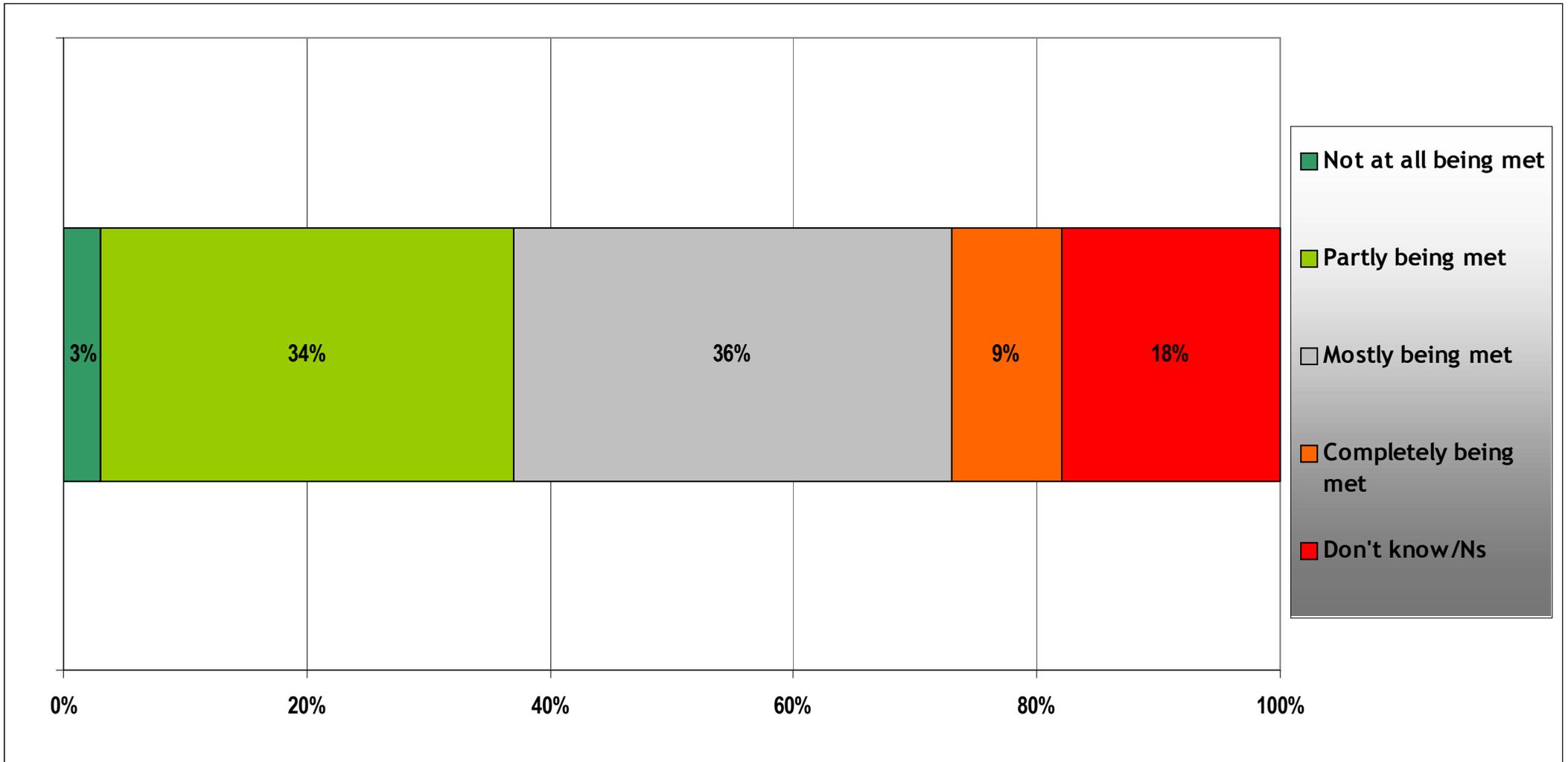
The significant increase in the number of Dignity Champions from mid 2008 onwards is thought to be due in part to the involvement of Sir Michael Parkinson.

### 7.3 Expectations of most Dignity Champions have been met

From the interaction with the Dignity Champions it is apparent that the majority of their expectations have been met. The graph, overleaf, presents the answers of Dignity Champions to the question seeking the extent to which their expectations of the Campaign had been met. 44% answered either 'mostly being met' or 'completely being met'. A third answered 'partly being met'.

During the site visits and the online focus groups, there was consensus between the Dignity Champions that their role became a lot clearer once a sufficient amount of time had elapsed. This was largely because with the passage of time they were more likely to have researched and understood what their role entailed.

**Graph 2: Extent to which expectations of Dignity Champions have been met**



## 7.4 A sense of empowerment

A number of Dignity Champions mentioned that the Campaign had empowered them. It was argued that by being part of the Campaign (specifically being identifiable as a Dignity Champion) had provided them with “leverage”. For many, this was very helpful in justifying the devotion of time and effort to their respective initiatives, and also in influencing peers and other colleagues (managers were commonly mentioned).

*“The Campaign has made me appreciate that I can make a difference without having everyone else around me doing the same thing.”*

**Dignity Champion**

*“A lot of people were treating patients with dignity and respect before the Campaign. However, the Campaign has allowed them to speak up about practices that impede patient experience. It galvanised those who had been advocating for greater patient dignity for a long time.”*

**Regional Dignity Lead**

One particular case study described how a small team of patients and volunteers had undertaken face-to-face dignity audits in hospitals for the local Trust. By being given this responsibility, the Dignity Champion felt that the patients were being listened to. Another example was of a website that allowed patients to anonymously share their experiences of staying in hospital. It was mandatory that each patient entry would receive a direct reply from the Trust.

The appointment of Sir Michael Parkinson as the National Dignity Ambassador has also proved very advantageous. The literature review and our fieldwork revealed that Sir Parkinson’s motivation and mere presence has given a boost to the overall awareness of the Campaign and what it seeks to achieve. Furthermore, it has also encouraged, inspired and empowered many to sign up as Dignity Champions.

*“I have followed Sir Michael’s online blog and it is gratifying to know that he cares so much about what this is all about.”*

**Dignity Champion**

## 7.5 Campaign resources and tools have supported action

The joint guidance developed by the Social Care Institute for Excellence and the Department of Health was deemed to be useful, especially by those working in social care settings. The guidance has been designed for people who want to make a difference and improve standards of dignity in care. It provides information for service users on what they can expect from health and social care services, and a wealth of resources and practical guidance to help service providers and practitioners in developing their practice, with the aim of ensuring that all people who receive health and social care services are treated with dignity and respect.

*“Whether you only have five minutes or five hours to gain an in-depth understanding, this guide has helped me to get some quick ideas. I look forward to it being updated.”*

**Dignity Champion**

The Dignity in Care Campaign website was mentioned as a key resource that has helped those interested and/or involved in the Campaign to learn, share and discuss. The regular updates on the website, the sharing of good practice case studies, information on local, regional and national events, and the discussion forums/podcasts were frequently mentioned as key enablers in taking action to promote dignity in health and social care services.

In late 2008, the Dignity Champion’s Toolkit for Action was made available on the website. This online toolkit was developed to provide Dignity Champions with ideas, information, advice and useful support materials to help them take action as Dignity Champions.

*“I have used the Toolkit and think it is a very useful tool. It has separate sections – a general one aimed at all Dignity Champions, one for health and social care staff and one just for members of the public – which make it suitable for all readership.”*

**Dignity Champion**

## 7.6 Dignity in Care case studies: a vast array of good practice across health and social care

A key element of the Review was to collate case studies that exemplify the sort of practices that the Campaign has addressed or is seeking to address. Dignity Champions were asked whether they had such stories to share in the online survey. A two page proforma was sent out to the 280 respondents who wanted to share their stories: out of these over 80 sent their proformas back. Despite a dozen or so

being anecdotal accounts of a bad patient experience, the rest detailed information on initiatives that ranged from the re-designing of patient gowns to carrying out targeted training for front line staff in care homes about the need to connect with patients' life stories of patients. All of the case studies have been written up as a stand alone document. However, we have determined a number of cross-cutting themes from analyzing the initiatives that we received.

#### *The Campaign is creating leaders and role models*

A large cohort of leaders have (and are) emerged as a result of their involvement in the Dignity in Care Campaign. These tend to be the Dignity Champions who first registered as part of the Campaign. In turn, these individuals have gone on to pioneer initiatives and activities that have sought to further patient dignity. Many have then orchestrated others to get involved in their peer groups. Some have then become the lead Dignity Champion in their respective organisation.

Where this has occurred, it is more likely that a host of initiatives have resulted and that dignity in care is strategically intertwined across policies and services. It seems that having a motivated individual behind a small initiative also seems to be more effective as they tend to be more focused on patient outcomes; with relatively larger initiatives – that tend to have more people and bureaucracy to counter - patient focus is not as effective.

#### *Patient choice, privacy and independence have benefitted*

Several case studies, especially those based in day care centre and nursing homes, reflect on efforts aiming to promote patient choice, privacy and independence among service users and patients. There are several examples of menus being revamped in order to offer patient choice or the example of a national chain of care homes setting up new small quiet seating areas around the premises for patients to have greater privacy. Similarly, there are other instances where privacy is being addressed via offering protected meal times. Appendix 10.1 showcases a couple of case studies – Arden House, Portsmouth City PCT and Anchor Homes - that reflect this.

Underpinning some of these improvements has been the effective involvement of patients in hospitals and residents' committees in care homes. For example, one case study mentioned how it introduced a variety of stimulating activities including a film and gardening club (respectively) as an outcome of greater input from residents.

#### *Training is helping to communicate and embed the importance of dignity*

The key objective of the Campaign was to stimulate actions that could be undertaken at regional and national levels to promote dignity in care and how it could be embedded in the daily practice. From the

case studies submitted, it is evident that several training programmes have been set up (or existing ones refined) on imparting the importance of safeguarding and promoting patient dignity.

In one case study, for example, it was noted that nutrition for patients in hospitals was identified as a major issue. A number of patients were forgoing food and were not happy with choice in their meals. The Dignity Champion not only worked to improve choice and nutritional content in the meals but also wanted to increase the role of meal mates, who could assist and join the patients, for the meal. A programme of training for the relevant staff followed across the concerned hospital first and then others across the PCT area. Appendix 10.1 outlines this in more detail in the form of a case study from the Royal Liverpool and Broadgreen NHS Trust.

#### *Greater partnership between health and social care*

There is evidence to show that in some areas the Campaign has encouraged strategic and operational co-operation between health and social services. In some instances, this has extended into the community and voluntary sector.

In most cases the partnership was initialised before the relevant activity was implemented; in some, it has been created after the activity was launched and it was deemed necessary to involve others.

Where this partnership has occurred, a programme of different initiatives on improving dignity in care is more likely than a sole activity. It is also apparent that where such collaboration has yielded a positive experience, the concerned individuals seem to be more likely to plan further activities in the future.

#### *The 10 point Dignity Challenge is being widely used*

The 10 point Dignity Challenge which has underpinned the essence of the Campaign is commonly referenced in describing how the different case study initiatives seek to improve patient dignity. In a number of cases they are also being used as a method for prioritising implementation and in performance measurement.

#### *Dignity Champions take pride in their role*

Both in the case study proformas collated and during the subsequent interactions with Dignity Champions (via the site visits and online focus groups), the sense of achievement being derived from the role was palpable. As mentioned earlier, many feel empowered by the Campaign, and are using it as a platform/lever to change practices by themselves and/or in partnership with others.

A number of case studies demonstrated that staff are being rewarded for their work by being nominated

as a Dignity Champion by their managers. This reflects on the strong impression that for many being identified as Dignity Champion is not just a means of identification but also as a matter of pride. One of the case studies provided details of how delivery drivers had been trained on the importance of nutrition so that they could better recognize early signs of problems in their clients as well as encourage them to eat.

The Input Assessment (DH, 2009) also notes the tremendous response to the “People’s Award for Dignity in Care,” which attracted 502 public nominations in 2009. This enthusiasm shows that individuals have reasons to be proud of the success that their initiatives have achieved. It also highlights how important dignity in care is to patient and carers, and how they want to be able to recognize and say thank you to those providing good care.

### *The Centre has played an invisible role*

The DH has been very keen for the Campaign to realise success. It has invested considerable time and effort into the campaign. However, the DH has chosen to ‘take a back seat’ by allowing action to be taken at the local level. Furthermore, it has not released rigid instructions and/or requested regular reporting and monitoring.

*“Compared to how other policy initiatives have been managed, we have largely been left to our own devices. It has not been pushed upon us. As a result, those who have taken part have done so because they wanted to and not because they had to. There is a big difference and consequently, many have relished the opportunity to be in the driver seat.”*

### **Regional Dignity Lead**

Therefore, the Campaign has the inbuilt capacity to be managed and owned by local players. The Input Assessment (DH, 2009) found that each region has hosted its own regional dignity events and dignity workshops. Moreover, a few of the government regions have also invested in creating pan-regional alliances. In mid-2009, the North West and Yorkshire and Humberside regions jointly funded and successfully hosted a regional event comprising of over 250 key leaders and influencers from across the two regions.

### *Widespread demands for the Campaign to continue*

There was a common perception among many of the respondents who took part in the Review that this Campaign has played a crucial and unique role in raising awareness about the importance of making sure that all services are delivered so that the dignity of those who avail them is safeguarded.

*“The Campaign was much needed largely because we required a push on dignity as other considerations and obligations were threatening to take priority in the way we work.”*

**Dignity Champion**

Underpinning this popular opinion was a concern that the DH would have to stop the Campaign in the near future. Many respondents mentioned that this was an initiative that could not have a short life span. On the contrary, the ethos of the Campaign was seen to be relevant in the longer term. Most were aware of the fact that the Dignity in Care Campaign was approaching its third anniversary. Spontaneously, a few of the Regional Dignity Leads asserted their view that the DH would not be able to carry this on in the longer term.

*“The Campaign is going to have to stop in its current form as the policy cycle is nearing an end. We can not stop that as this is how national policy works and there are justifiable reasons for that. But, this is a critical moment if another way is not found to sustain this then we could lose a lot of what has been gained.”*

**Regional Dignity Lead**

When asked about the means through which the Campaign could be sustained into the future, the overwhelming response was that it had to be owned and led by those at the local level. Many mentioned that local networks (formal and informal) of local statutory (i.e. local authority and PCT) and non-statutory (Community and voluntary groups) stakeholders could play the crucial role.

*“Just in the way we have the experience from Local Strategic Partnerships and Local Area Agreements comprising of local agencies and individuals collaborating strategically and operationally on key issues, dignity in care also needs to be streamlined as an issue for collaboration.”*

**Regional Dignity Lead**

*“With the right incentives, I am sure the Campaign’s focus could be maintained. Those involved in local scrutiny structures could be called upon to take on a proactive role.”*

**Dignity Champion**

## 7.7 Promoting dignity in health and social care services

As mentioned in the introduction of this review, attributing causal relationships between the Campaign and the progress achieved nationally or regionally is just not possible. This is largely due to the sheer number of initiatives related to dignity and respect that are/have been undertaken as well as the complexities of quantifying dignity in care. Instead, our analysis of the Campaign has focused on identifying the successes and areas for improvement. Underpinning this, are the assumptions that we have employed to base our judgement on.

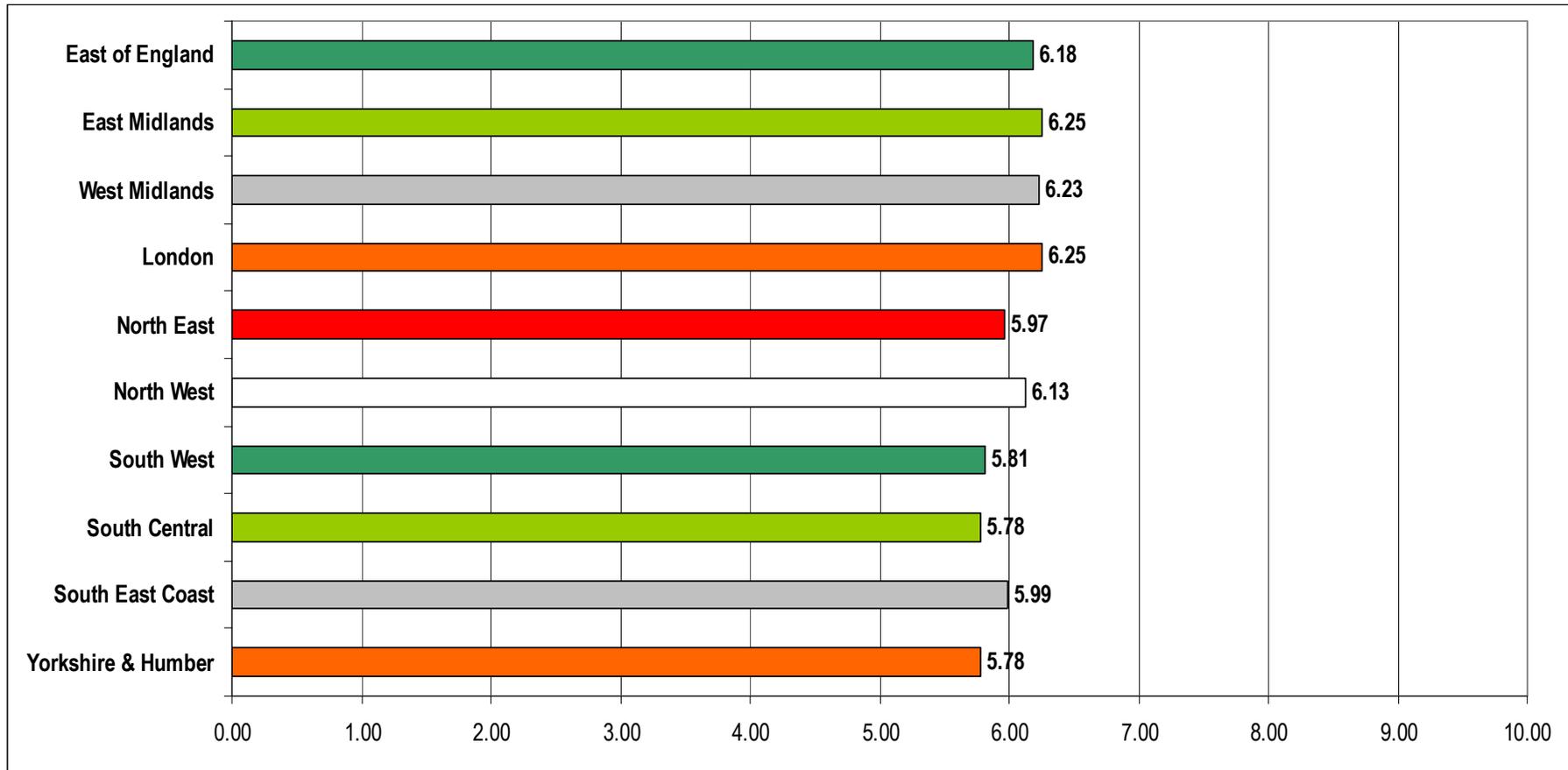
The literature review that we carried out in the first phase of the research revealed a number of other initiatives that are related to the Campaign, such as a programme of activities on long-term conditions and same-sex wards. As a result of this onus on dignity, it can be stated that a greater focus on dignity has been promoted over the last few years. The prioritisation of maximising patient experience has meant that ensuring dignity and respect to a service user is essential in the overall scheme of things.

The surveys with Leaders in health and social care and Dignity Champions (respectively) exemplified this. Firstly, in response to a scaled question seeking the extent to which the emphasis on dignity through the Campaign helped promote dignity in care in their organisation, 142 out of the total 179 Leaders in health and social care respondents who were aware of the Campaign (79%) provided an answer falling in the 5 to 10 range (with 10 being helped a lot). The mean score for this question was 6.20.

The same question for the Dignity Champions generated 1,147 responses. Graph 3, overleaf, shows the mean of the answers according to each of the nine government regions. As shown, the lowest score was in South Central (5.78) and the highest was in East Midlands and London (both at 6.25).

In order to assess the impact of the Campaign, we also asked the Leaders in the health and social care survey about the extent to which dignity in care is a priority at Board level in their organisation. Twenty percent out of the 220 pool of respondents stated that it is a very high priority. The mean score for this question 7.91.

**Graph 3: Extent to which Dignity Champions believe dignity in care has been promoted**



## 7.8 Findings from the Dignity Metrics report

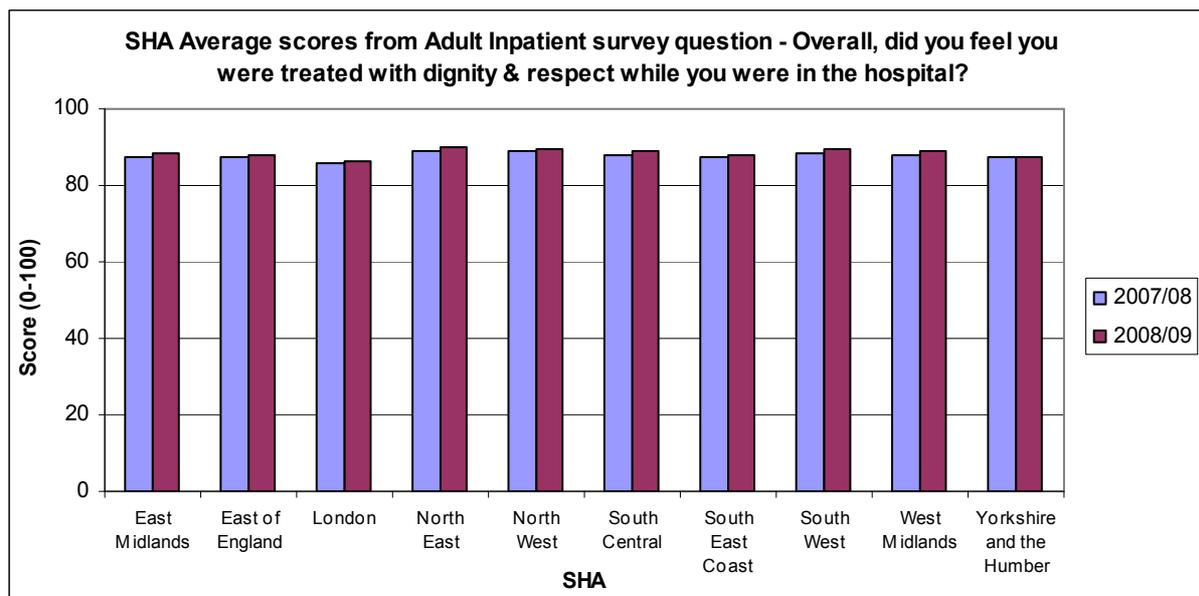
The Dignity Metrics report (NHS Information Centre for health and social care, 2009) outlines a body of quantitative evidence which indicates a number of successes for the Campaign both in health and social care. These include:

### Health care

#### *Patient care practices are improving*

The Adult Inpatient Survey is a well established method for assessing the experience of patients on a self reported basis. It provides a valuable insight into what patients feel about the care they have received.

A number of questions related to dignity appear in the survey across the 2005/06 to 2008/09 period and this allows a time-series analysis to be performed. The questions analysed in the Dignity Metrics report were chosen on the basis that they were deemed to have a significant effect on a patient's dignity when receiving hospital treatment. The main findings from this survey give a positive message of dignity practices. For example, the average score for trusts within every SHA rose between 2007/08 and 2008/09 for the question 'Overall, did you feel you were treated with dignity and respect while you were in the hospital?' The graph below (which is reproduced from the Dignity Metrics reports) shows the respective average score for each SHA region.

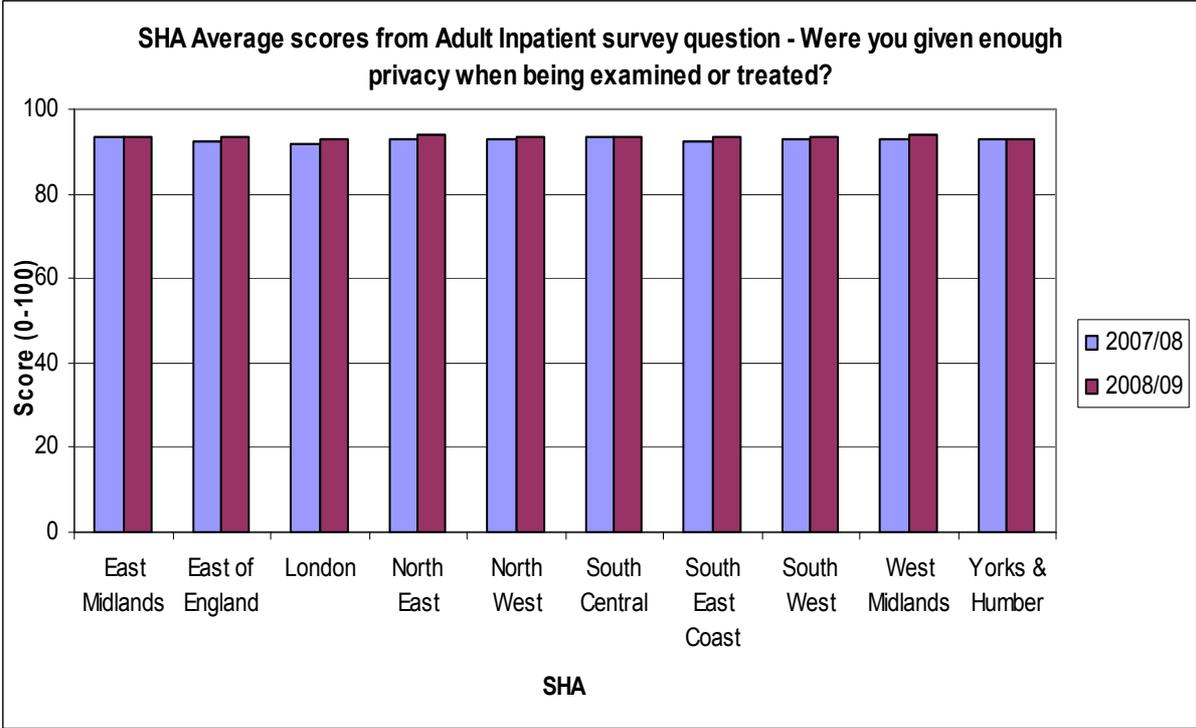


The overall average for England for the same question is shown in the table below.

Year	National average
2005/06	88.2
2006/07	87.8
2007/08	87.7
2008/09	88.3

Despite the fact there is an upward trend between 2007/08 and 2008/09 figures (as also visible in the chart above), there is no notable change on a national level between 2005/06 and 2008/09.

The trend for improvement is also shown in the question ‘Were you given enough privacy when being examined or treated?’ As the graph (which is reproduced from the Dignity Metrics report) shows, each SHA showed an improvement between 2007/08 – 2008/09.<sup>3</sup>



<sup>3</sup> The analysis used 2 years of data on a selection of the question because of the re-structuring of SHA's & PCT's during 2005-06. As the results are presented in SHA format, it was felt unwise to present results for the year when the re-structuring took place.

The overall average for England for the same question is shown in the table below.

Year	National average
2005/06	93.3
2006/07	93.0
2007/08	92.7
2008/09	93.4

The analysis shows fluctuation between the years with a fall in the average for the first three years but the trend is reversed between 2007/08.

Upward trends between 2007/08 and 2008/09 can also be seen for the question, ‘Were you given enough privacy when discussing your condition or treatment?’ Only one SHA failed to see an improvement in its scores.

Similarly, the question ‘Did you get enough help from staff to eat your meals?’ also saw an improvement in average scores for the same time period in all but one of the SHA’s. The graph, below, presents the average score for each SHA region for this question.

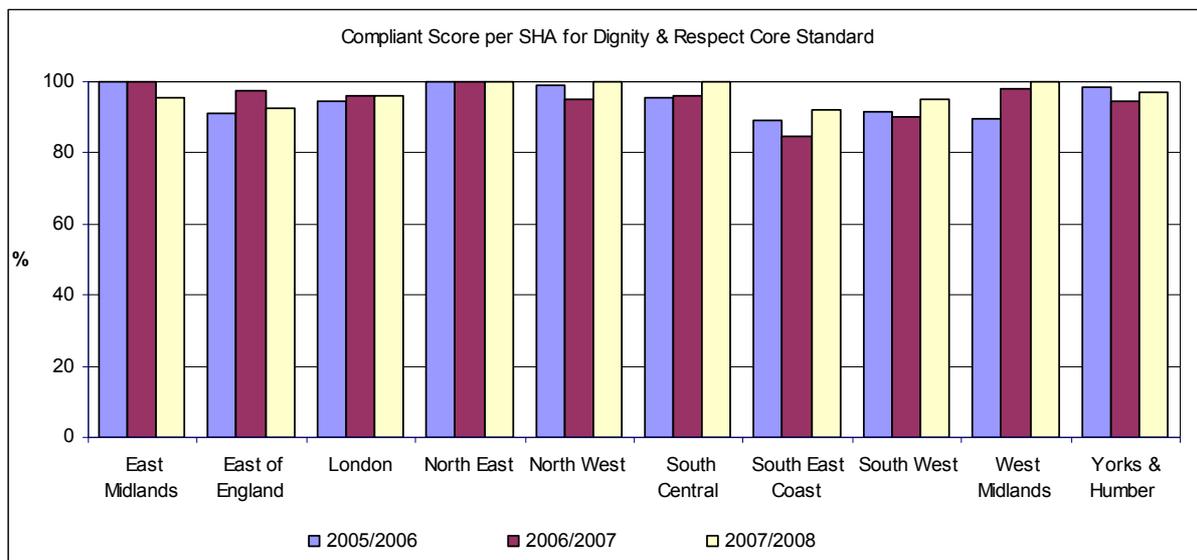


The Dignity Metrics report analyses a number of further questions. These can be accessed by using the link: <http://nascis.ic.nhs.uk/Portal/Library.aspx> Any queries regarding the document and its content should be made in the first instance to the NHS IC's enquiries facility (Tel: 0845 300 6016 / email: [enquiries@ic.nhs.uk](mailto:enquiries@ic.nhs.uk)). From here the enquiry will be directed to the Social Care team.

### Core Standards on Dignity and Respect

The Core Standards are a set of standards which each individual trust is measured against on an annual basis. Within the standards there are 24 categories that are measured upon: trusts receive one of three ratings – Compliant, Insufficient assurance and Not Met - against forms they submit.

The Dignity and Respect Core Standards exist to ensure that healthcare organisations have in place systems that treat patients, their relatives and carers with dignity and respect. The following graph shows a picture of gradual improvement or maintenance of the Dignity and Respect standard for most of the SHA's with some rises and falls in the intervening year.

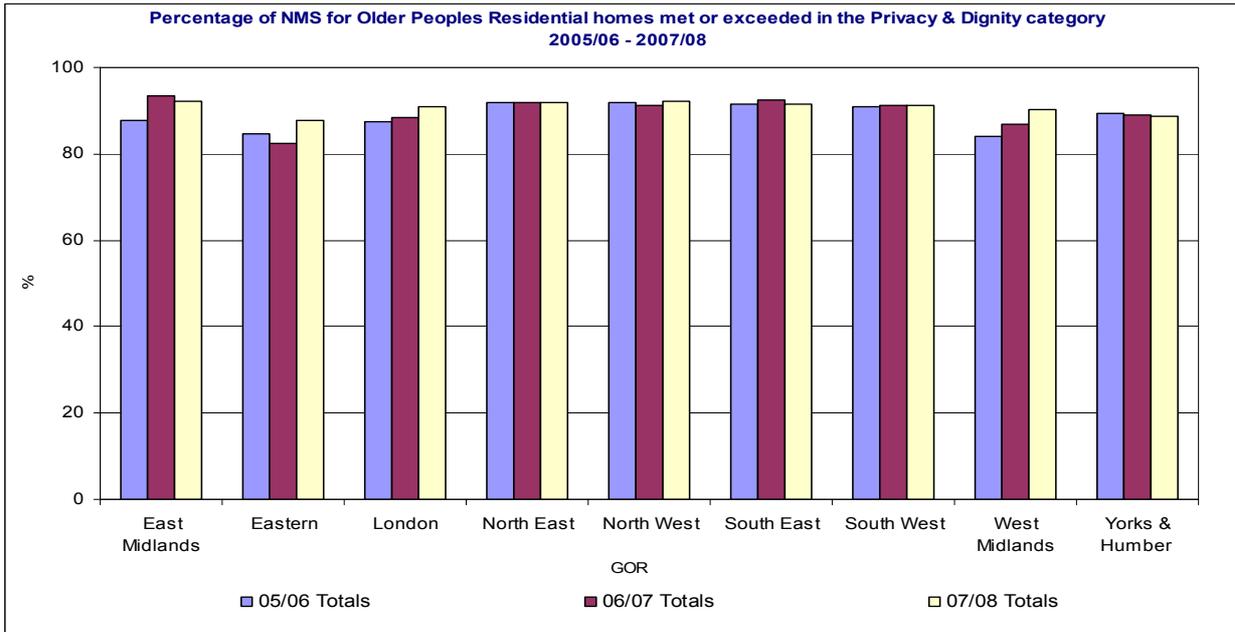


### Social care

#### Increase in Privacy and Dignity standards

The examination of the social care related data sources produced some key findings. The National Minimum Standards for older peoples' care homes shows that the proportion of homes either meeting or exceeding the standards in the Privacy and Dignity category has risen consistently across the period 2005/06 – 2007/08 in all but one government region where it has consistently fallen, though this was only by a nominal amount. On a national level, 91% of homes either met or exceeded the standard in 2007/08; whilst the figure was 89.2% in 2005/06.

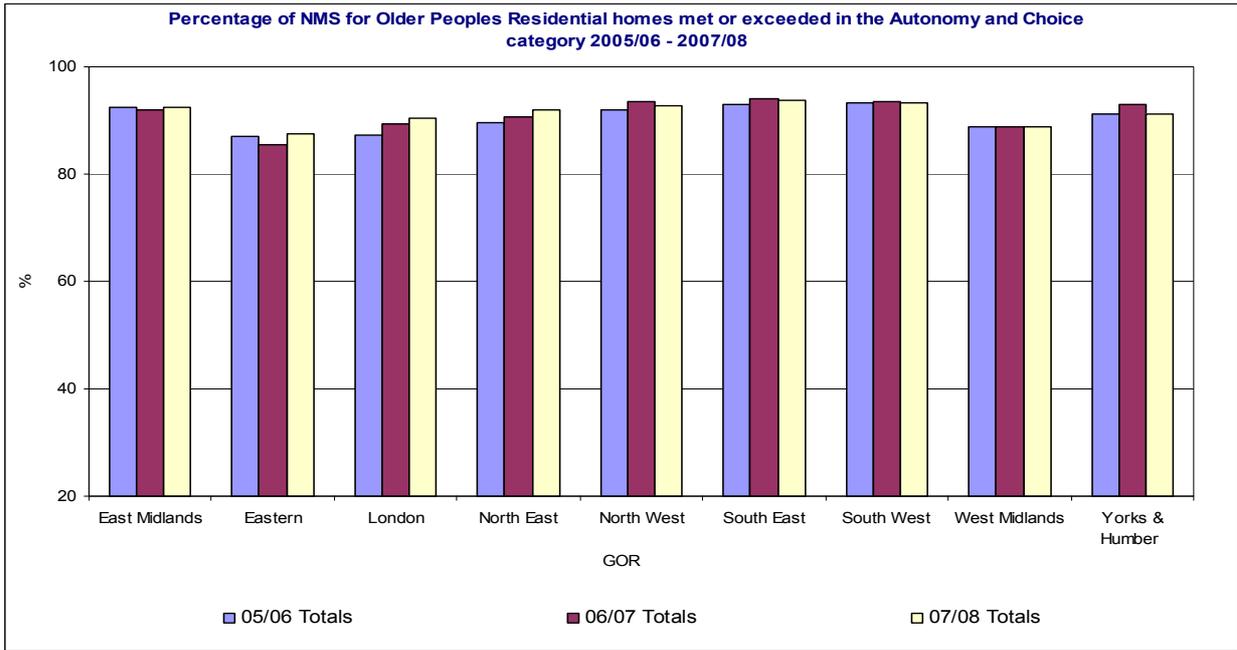
The bar chart, overleaf, is taken from the Dignity Metrics report and shows how homes within each government region were rated against the National Minimum Standards for Privacy and Dignity.



***Similar increase in Autonomy and Choice standards***

A similar pattern exists in the Autonomy and Choice Standard. All but one government region had a higher proportion of homes meeting the standard in 2007/08 than they did in 2005/06. On a national level, approximately 92% of homes met or exceeded the standard in 2007/08; the figure in 2005/06 was 91%.

The bar chart, overleaf, is taken from the Dignity Metric report and shows how homes within each government region were rated against the National Minimum Standards.



## 8. Shortcomings of the Campaign

### 8.1 Lack of time has impeded Dignity Champions

In our survey of Dignity Champions, we asked respondents to outline the key barriers that they had encountered in the Campaign. From the analysis, it is apparent that there is no single major barrier that has affected progress. Instead, the feedback from the total 1,147 pool of respondents is spread thinly across a large range of barriers. In total, 44 different types of barriers were identified. These ranged from ‘General lack of time’ (which got the highest percentage of respondents at 16%) to ‘Bureaucracy’ (1%). Surprisingly, the general lack of finance only attracted 3% of the respondents.

Seventeen percent of the respondents stated ‘Nothing in particular’. Table 3 below shows the breakdown of Dignity Champions according to role/setting and the top 5 barriers that they identified. As the breakdown suggests, the views were very similar.

**Table 3:**

Top 5 Barriers in carrying out role	Health Care/ Social Care	MP/ Councillor	Voluntary/ Advocacy Organisation	Member of Public	Local Involvement Network	Other
General lack of time	155	1	8	1	0	6
General lack of understanding	61	0	4	1	0	2
Empathy/General lack of care	58	0	5	1	0	1
Attitudes/Mindset of staff/colleagues	52	0	4	0	1	2
Lack of promotion/awareness	43	0	7	2	1	3
<b>Total for 5 key barriers</b>	<b>369</b>	<b>1</b>	<b>28</b>	<b>5</b>	<b>2</b>	<b>14</b>

### 8.2 Variance in measuring patient feedback

A key objective of the Review was to demonstrate and measure change in the opinions of service users and patients about the quality of their care, and views on whether Campaign interventions have succeeded. From the analysis of the insights gained from the surveys, case study proformas, site visits and online focus groups, there appears to be a lot of variance in the extent to (and quality of) the impact on patients being identified, measured and tracked. This is despite a high level of awareness that activities need to be measured for their effectiveness.

Firstly, Leaders in health and social care were asked in the survey whether they were aware of any procedures/indicators being employed to measure dignity in care within their organisations. Out of the total pool of 220 respondents, only 48% answered 'Yes' (34% did not provide an answer and 23% chose 'Don't know').

Out of the 106 that answered 'Yes', the top three answers were 'Patient experience/feedback'; 'Patient surveys'; and 'Essence of Care benchmarking' (each receiving 19% respectively). Answers such as 'Complaints analysis' and 'Ward surveys' were relatively less common (8% and 2% respectively). From the case study analysis and the online groups, it was apparent that the availability of guidance and specific toolkits (recommended by the DH) to measure impact would be highly beneficial.

*"There are a lot of toolkits around. We need something that DH can vouch for."*

**Regional Dignity Lead**

### **8.3 Many initiatives have helped services to achieve minimum standards**

A number of the case studies clearly describe activities that could be considered a normal aspect of routine care and not a service initiated over and above it. While this is a positive outcome, the Campaign was aimed at inspiring Dignity Champions across all settings to go the 'extra mile' and take the step of providing something over and above their everyday service. By describing initiatives that have focused on providing what many would deem a minimum service there is an argument that the Campaign has largely resulted in improving services so that they can fulfil the lower end of patient expectations.

### **8.4 Challenge of influencing senior leaders**

Although several of the participants in the survey felt that ensuring services maximise patient dignity and respect (in the ways they are planned and delivered) had become a bigger priority at the board level, there was a feeling that a lot more still needs to be done to foster change at the middle and higher management. A number of Dignity Champions mentioned that the progress that had been achieved around the regions would be jeopardised if the concerned individual(s) left their post and/or were promoted. As the Campaign has primarily relied on individual and local action, this remains an important obstacle to overcome.

While putting individuals at the centre has many advantages, it has also had a significant drawback. This being that the concerned individuals have tended to be frontline staff rather than senior level

employees. Whereas the patients and service users who come in to contact with these individuals directly have benefited, others who do not come across them have not. This is because in many instances the Dignity Champion initiatives are targeting a specific locality and/or a unique patient group. Those who do not fall in to the catchment area or target group may not benefit.

*“What we have achieved in our area is something that we are proud of. Many people have come to us from other areas but we can not cater for them as they fall out of our remit. It is very frustrating for everyone.”*

### **Dignity Champion**

At the same time, a couple of case studies received from Dignity Champions in hospitals show that networks of Dignity Champions are being systematically managed and developed in order to create an active resource that can share and develop good practice together. Appendix 10.1 presents a case study from Luton and Bedfordshire NHS Trust exemplifying this.

## **8.5 Findings from the Dignity Metrics report**

### **Health care**

#### ***NHS trusts can improve much more in relation to privacy and confidentiality, dignity and respect***

The Core Standards data provide a picture of how NHS trusts perceive they are performing in terms of meeting the Privacy and Confidentiality standard. The Dignity Metrics report states that “the trend is not very positive but neither is it one of deterioration. The levels of compliancy for this standard are at virtually the same level in 2007/08 as they were at 2005/06 and there was a notable drop in levels of compliancy in the 2006/07 year.” At a national level in 2007/08, levels of compliancy for the Dignity & Respect and Privacy & Confidentiality standards were at 97% and 95% respectively. The Dignity & Respect standard has shown consistent improvement at a national level across the 2005/06 – 2007/08 years in terms of the percentage of health care sites achieving complaint status with the standard.

## 9. Conclusions and recommendations

In order to ascertain the overall success of the Campaign it is important to revisit its overarching objectives as outlined in the introduction. The first of these was on:

- Raising awareness and stimulating a national debate around dignity in care
- Inspiring and equipping local people to take action
- Rewarding and recognising those who make a difference

### *Raising awareness*

In terms of raising awareness, our review has found that dignity in care is a higher priority than it was in the past. From the feedback of the Key Thought Leaders, Regional Dignity Leads and Dignity Champions that have participated in our research, it can be seen that the importance of dignity in care is being recognised. The onus on giving patients and service users a better experience entails improving the way services recognise individual needs and preferences. The drive to foster greater patient choice across health and social care has augmented this. Despite such external policy drivers, the Campaign has played a direct role as well.

### *Inspiring and rewarding*

The large part of the Campaign's focus was on nurturing action at the local level. The number of Dignity Champions that have been inspired to sign up is considerable. However, this is a very small number when compared to the total health and social care workforce. However, it was not the intention of the Campaign to make every single employee a Dignity Champion.

As this Review has found, many individuals have taken immense pride in their efforts to improve dignity in care. Likewise, a number of case studies show that employers are using the Dignity Champion role to motivate and reward such positive behaviour.

### *Embedding a common understanding*

The second objective of the Campaign was to create a common understanding of what dignified health and social care services look like. In this regard, our review has found that more time is needed before these aims can be met. Getting the message across about what constitutes a dignified service is a very complex task. It is one that this Campaign can help with – for example by making available training and guidance packs aimed at those working in domiciliary and residential care - but not achieve on its own. Instead, it needs a concerted effort from those training, recruiting, managing and monitoring these services.

At the same time, the Campaign's 10 point Dignity Challenge has been very well received by those that have taken part in this review.

### *Prioritising dignity via consistent communications*

The third overarching objective was to communicate dignity as a priority through consistent messages and inclusion in key guidance produced by DH and other stakeholder organisations. The Input Assessment (DH, 2009) provides details and breakdown of usage of the different resources used to communicate dignity as a priority. It is evident from that report that the Campaign has invested in a well thought out and comprehensive plan to communicate a vision for dignified care. This plan used levers such as the Dignity Tour in 2008 that increased the number of Dignity Champions at the time by four times to the Online Practice Guide. A National Helpline for Dignity Champions has also been used to help individuals get information about the Campaign and sign up.

### *Linking dignity with other policies*

The Campaign has also attempted to intertwine dignity in care with other policies and guidance. For instance, a Beacon Council Scheme for Dignity in Care was set up in 2007/8 with the Improvement and Development Agency (IdeA). The Scheme was supposed to identify exemplar local authorities and then support them to share and disseminate their good practice. The winners, Warrington Borough Council, were awarded beacon status in March 2008. They have undertaken a range of activities and peer support, both nationally and locally, to support other councils to learn from their approaches to dignity in care.

Similarly, nutritional care and assistance with eating has been a key dignity issue raised throughout the Campaign. In recognition of this, the Campaign brought together a wider range of stakeholders with an interest in this area and set them the challenge of working together to help address these issues. The *'Nutrition Action Plan: Improving Nutritional Care'*, was published on 30 October 2007. It outlines how nutritional care and hydration can be improved and suggests five key priority areas through which managers and staff working in health and social care can address this. The key priorities for action are to:

- Raise awareness of the link between nutrition and good health
- Ensure that accessible guidance is available across all sectors and
- Encourage nutritional screening for all people using health and social care services

The outcomes of the Plan will be published in late 2009 in the shape of the Nutrition Action Plan Delivery Board End of Year Report.

## **9.1 Would this have all happened without the Campaign?**

In the various interactions with Regional Dignity Leads and Dignity Champions, it was asked whether the initiatives that had been started (and the ensuing progress) would have happened without the

Campaign. The vast majority felt that while they probably would have occurred, the associated scope, will power, level of planning and overall impact would not have been as evident or systematic.

*“Being under the umbrella of the Campaign has meant that the message that ‘this is all about the importance of working to meet needs and expectations of users’ has been easier to get across. Without the Campaign much of what we have achieved would not have happened as the strategic oversight would have been missing.”*

**Regional Dignity Lead**

As mentioned already, a number of national forces and drivers have also had an impact. In particular, the patient choice and personalisation agendas have enabled services to be more responsive to patient expectations and needs. In the NHS Information Centre's Dignity Metrics report, it is stated that a study carried out in 2006/07 concluded that 92% of 1.5 million patients thought the NHS had become more patient centred.

In essence, the Campaign has provided the strategic and logistical support for those willing to take on the Dignity Challenge. For example, the issuing of credit card sized cards that set out the 10 point Dignity Challenge and included information on how people can sign up as Dignity Champions were useful in not only raising the overall profile but also served as useful information and guidance. Indeed, the DH has found that to date well over 300,000 Dignity Cards have been issued, on request only, to Dignity Champions. These in turn have been distributed locally to further raise awareness of the Campaign and the Dignity Challenge.

A capital grant of 67 million pounds was also made available as a component of the Dignity in Care Campaign. Approximately 4,500 Care homes across England received a share of the grant to help improve the care home environment in order to provide more dignity for residents and service users. The DH Input Assessment (2009) lists the various improvements that have resulted.

## **9.2 Key recommendations**

In light of the key findings from our Review, we would make the following recommendations. It is important to note that some of these are already being considered by the DH:

### **Clearer guidance on measuring and tracking patient experience**

One of our main findings from the case studies collated in this review is that patient experience is not being measured in a consistent manner. On the one hand a number of initiatives seem to have prioritised this by implementing formal and informal mechanisms of collating patient feedback on a

regular basis. However, for others it appears that patient experience is not being assessed as well and/or as regularly. Linked in with the feedback about the need for specific evaluation tools and guidance from the Dignity in Care (mentioned earlier), we would recommend that the Campaign place a bigger emphasis on this area. The Project Team may also consider highlighting patient feedback in the future in a more distinct manner on the website.

At the national level, it will be important to regularly analyse dignity metrics. This is because these provide a wider picture of progress and help in establishing a national perspective. It may be advisable to benchmark the metrics reviewed in the Dignity Metrics report for any future assessment.

### **Letting stakeholders take charge**

A key finding from our Review is that the Campaign has achieved what it has because it has primarily allowed local people to take action on local issues that they feel need addressing. Instead of issuing stringent guidelines and adopting a one size fits all approach, the Campaign has embraced a bottom up ethos. This has resulted in lots of small and often dispersed interventions that are reaping good outcomes. And the feedback from those involved in the Campaign indicates that local stakeholders have a key role to play in the future.

The DH Dignity in Care Project Team share these views and have recently invited a wide range of stakeholder organisations to join a national Dignity in Care Stakeholder Partnership Board with a view to the partnership board and its member organisations ultimately taking responsibility for taking the campaign forward in the longer term. Our recommendation would be to allow a smooth transition by investing in dialogue with those who may be able to take the initiative forward. This handover will only be effective if procedures and protocols of the new Campaign 'owner(s)' are properly identified and agreed beforehand.

### **Informing those directly and indirectly involved about the future policy course**

It was mentioned earlier in this report that many of those engaged in our review were concerned about the future of the Campaign. There is widespread support for the Campaign to be taken forward by local stakeholders. However, there is a sense of uncertainty prevalent and individuals are looking to the DH for a sense of direction on what the future holds.

*“What I think will happen is my isolated view. Only the Department can provide us with the answers.”*

**Regional Dignity Lead**

DH acknowledges that the campaign cannot be led from Government in the longer term and has deliberately designed the campaign with the inbuilt capacity, through the Dignity Champions network

and the engagement of stakeholder organisations from the outset, to be led locally in the future. Indeed, with now over 10,000 Dignity Champions, it is already starting to take on a life of its own in the true sense of a social movement, which is what the campaign is intended to be.

By using the mediums – website, regional events and pod casts - that the Campaign has so successfully already employed, others can also be involved in this process. Specific threads on the chat forums as well as polls on how the Campaign could be rolled out in the future are a way of beginning this interaction.

### **Communicating successes more widely**

The review has found that the Campaign has played a vital role in a lot of local places for a lot of people (both patients and staff). The numerous case studies that we have come across provide examples of such outcomes.

It is our recommendation that these successes are communicated more widely. There is also a sense amongst some of those engaged that this effort also needs to be done in a more proactive manner. Indeed, the analysis of the Dignity Champions survey shows that ‘increased public awareness’ was seen to be the most popular change that would improve the impact of the Campaign (11% of 1,147 total respondents). We concur that the target group ought to be the wider public as those already involved are well catered for by the DH and through the mediums it has used.

*“I know that we have to be conservative about our successes but we need to be positive in a proactive manner in this area.”*

**Dignity Champion**

*“The newspapers are filled with scare stories...we need to counter this.”*

**Dignity Champion**

The approaching third anniversary of the Campaign offers a good opportunity in this regard.

### **Emphasising dignity and respect for staff as a priority**

A number of times, Dignity Champions raised the importance of making sure that staff (especially those at the frontline) felt valued and rewarded by their employers. This view was supported by the belief that unhappy staff are less likely to embrace the messages entailed by the Campaign.

*"If I do not feel valued and am overburdened by those who I work for and with then why will I want to do things differently."*

### **Dignity Champion**

Our recommendation would be for those leading the Campaign both now and in the future to recognise this link and stress its importance accordingly. Obviously, the DH can not widen the focus of the Campaign but it may be able to communicate that staff need to have a conducive environment for them to work as effectively. Making links with programme and policy streams that do focus on improving staff working practices in health and social care would be beneficial.

## 10. Appendices

### 10.1 Exemplar case studies

**Organisation name:** Portsmouth City PCT

**Region:** South Central

**Date the initiative started:** 2008

**Date the initiative finished (if appropriate):** Ongoing

#### **Overview:**

The Dignity Champion was instrumental in establishing the Dignity garden completed for Exbury Ward which is for elderly patients, some with mental health problems. The ward had been on the first floor which the Dignity Champion deemed to lack any dignity for the patients who would never be able to look at or walk out onto a piece of grass from there. He campaigned for a move to a ground floor site with an adjacent plot of land, and with the move completed the scene was set for the Dignity garden.

#### **Planning and preparation:**

The Dignity Champion was aware of the undeveloped piece of land adjacent to the re-located Exbury ward and after one meeting, secured agreement for the go-ahead to plan a garden to suit the patients. Much care was taken in the design of the garden to make it appropriate for the patients on that particular ward. It was to be flat to avoid falls, to have continuous paths to avoid dead-ends, raised beds to enhance the enjoyment for wheelchair users, and plants that could be touched and smelt. Various other safety measures also had to be taken into account but above all the garden was to be for relaxation and pleasure and to enhance the dignity of the patients.

#### **Implementation/who helped and how?:**

The company maintaining the gardens will be employing some ex-patients from the hospital, some with learning disabilities so the benefit of the garden extends to offering the dignity of work to some who may otherwise have difficulties in finding employment. Patients are encouraged to use the garden as they please. As the ward opens onto it, patients can freely and independently make use of it. The garden was officially opened by a patient on the ward, an ex-England and Pompey player, in the presence of the FA cup and several of his ex-playing mates.

#### **The outcome of the initiative(s)**

The chief measures of the garden's success are the smiles on peoples' faces. Its tranquil effect has also been noted in its influence on patient behaviour as illustrated by one patient with anger problems who uses the garden to calm himself.

Moving on from this project, the new facility about to open at Portsmouth City PCT has also been planned with carefully-designed rooms and gardens to provide the best possible facilities in which patients can experience some privacy and dignity.

**Organisation name:** Arden House Nursing Home

**Region:** East of England

**Date the initiative started:** 2008

**Date the initiative finished (if appropriate):** Ongoing

**Overview:**

The Dignity Champion at Arden House Nursing Home has introduced a specific initiative with regard to patients' choice of meals to ensure that individual requests are understood and met. A staff member sits down with every resident every day to discuss their choice of meal. In addition, patients are presented with a menu album showing pictures of all food offered at the nursing home enabling everyone to make an informed choice. This is aimed especially at patients whose first language is not English as well as patients who may suffer from dementia or deafness. It had been noted that sometimes patients did not realise what they had selected or that they just agreed to a suggestion if they did not understand what they had to do.

The manager thought of this idea when he worked in another care home. There he found that staff seemed to be making the meal choices for residents whose first language was not English and for those who were hard of hearing, as neither group was able to understand fully what they were being asked to do.

**Planning and preparation:**

The manager spoke to the cooks who were in favour of working with this scheme. Staff were also willing to speak to patients each day about their meal selection.

**Implementation/who helped and how?:**

The pictorial menu initiative involved all colleagues including nursing staff and kitchen staff at the nursing home along with the proprietors, the residents and their friends and relatives.

**The outcome of the initiative(s):**

Reaction to date has been positive all round. Relatives of the patients in particular express their satisfaction at the introduction of an additional element of choice. These are the factors that help provide some dignity for patients who are mainly dependent on others for almost everything.

Measurement will also be taken from replies to the annual satisfaction survey completed by patients. There is already a question about satisfaction with food but another will be added to ask patients their opinions on the use of photographs.

**Organisation name:** Royal Liverpool & Broadgreen NHS Trust

**Region:** North West

**Date the initiative started:** 2006

**Date the initiative finished (if appropriate):** Ongoing

**Overview:**

The Royal Liverpool & Broadgreen NHS Trust has an active Champion Network for Older People which is attended by internal staff (a range of professions and grades) and external stakeholders which is chaired by the Dignity Champion. The work programme for the network identified the need to continue a focus on food and nutrition, given the Age Concern report Hungry to be Heard (2006) which highlighted the problems with meals and nutrition amongst elderly hospital patients. With this in mind the group targeted a health care assistant on every ward and provided them with a full day's training which covered issues regarding swallowing, monitoring, the Malnutrition Universal Screening Tool (MUST), puree diets, a visit to the hospital kitchen etc. The training was provided by senior staff on the Network.

**Planning and preparation:**

The incentive for the Dignity Champion to take on a nutrition programme was the Help the Aged 2006 report about nutrition problems for the elderly in hospital. The Dignity Champion was involved with the Trust-wide nutrition group and it was already known that the Royal Liverpool had issues regarding frail patients and nutrition which needed to be addressed. The outcome of this was the training aimed at the health care assistants.

**Implementation/who helped and how?:**

The training days were evaluated with such a positive result that the Network has now agreed to deliver the same programme to all Health Care Assistants (HCA) in the organisation. The course sought to make the HCA take real pride in their learning and this was underscored by the presence of a senior manager who introduced the training day and highlighted the importance of their role. Also offered to attendees was a "goodie" bag of related documentation and other items which were also well-received.

**The outcome of the initiative(s)**

The Trust's MUST compliance has not been good to date. The benchmark for this exercise was the MUST results which will continue to be audited. The aim of the exercise will be to see an improvement in patients' nutrition which is the expected result of the new training.

Opinion Leader

**Organisation name:** Luton & Bedfordshire NHS Trust

**Region:** East of England

**Date the initiative started:** 2008

**Date the initiative finished (if appropriate):** Ongoing

**Overview:**

The Dignity Champion, a practice development practitioner, has, together with other colleagues, provided training and workshops on behalf of the Luton & Bedfordshire NHS Trust. The training was based on the 10 Dignity points. The outcome of these initiatives has had an impact in several areas including the running of wards and the co-operation of Champions in different areas to ensure the spread of good practices and the challenge of poor practices.

**Planning and preparation:**

Change was initially nurtured through training and workshops set up by the Dignity Champion. A pilot scheme took place on three wards and this will now be extended. A Dignity Champions' workshop will also take place to further the initiative.

**Implementation/who helped and how?:**

The implementation of the Dignity in Care initiatives has now spread to everyday practices via the establishment of a dozen Dignity Champions in the Trust and at least one Dignity Lead on each ward. When the Champions first met to discuss their role, they each made a pledge. This will be followed up at each subsequent meeting to assess progress.

**The outcome of the initiative(s)**

The effects of good practice have spread with the result that: gender separation exists on wards, 16 dignity pledges are being followed through by the Dignity Champions, a new quiet room has been set up for patients and relatives and a faith room has also been introduced.

Now it has become standard to work together with other champions to spread the good work practices.

The progress reports made by the Dignity Champions at the regular workshops will be audited and reviewed.

**Organisation name:** Anchor Homes

**Region:** London

**Date the initiative started:** 2008

**Date the initiative finished (if appropriate):** Ongoing

**Overview:**

The four staff members who were Dignity Champions at this London Anchor Home set up a project in which new quiet areas would be created round the home for the residents. Previously, residents had only been able to sit in the dining area or the lounge where the television is on. Now it is possible to sit, read, chat, look at photos or look at the view in a quiet atmosphere in a choice of locations.

**Planning and preparation:**

The staff members had a few meetings to decide on how to improve the environment for residents. They identified some quiet areas in the home where a few chairs and tables could be added. They then obtained finance from the manager to buy some coffee tables and have now set these up with newspapers and magazines.

**Implementation/who helped and how?:**

The dignity initiative involves the residents, colleagues, the manager and the activity coordinator of Anchor Homes.

**The outcome of the initiative(s)**

Patients are voting with their feet and making use of the new spaces.

## 10.2 Surveys

### Dignity Champions survey

On November 14th 2009, the Dignity in Care Campaign will be three years old. In order to measure the success of the Campaign and understand its impact on services and people receiving them, the Department of Health has commissioned an independent organisation, Opinion Leader, to carry out a confidential consultation to review the Campaign's impact to date.

Understanding the perspective of Dignity Champions is absolutely crucial to this review. We would be very grateful if you could take the time to complete the survey below. At the end of the survey, you will also be invited to participate in further research activities being carried out by Opinion Leader as part of the Consultation, in order to share your thoughts and views of the Campaign and any issues you have come across relating to dignity in care in more depth.

The views you express in this survey and in any further consultation will be treated in absolute confidence.

We will be donating £1 to a charity of your choice for the first 500 surveys completed in this Consultation.

Please Note: If you are not a Dignity Champion but do work in health or social care, we would like you to complete an alternative survey. Please contact Jean Ledger at Opinion Leader ([jlledger@opinionleader.co.uk](mailto:jlledger@opinionleader.co.uk)) for more information.

There are currently over 9,000 Dignity Champions, from a wide range of backgrounds. In what capacity did you volunteer to become a Dignity Champion?

- Health care or social care employee
- MP/councillor
- Member of voluntary sector / advocacy organisation
- Member of the public
- Local Involvement Network (LINKs)
- Other (please specify):

Where do you work as a Dignity Champion?

- East of England
- East Midlands
- West Midlands
- London
- North East
- North West
- South West
- South Central
- South East coast
- Yorkshire and Humber
- Wales
- Scotland
- Northern Ireland
- Other (please specify):

For how long have you been a Dignity Champion?

- 1-6 months
- 7-12 months
- 1-2 years
- 2 years +

What was the reason you decided to become a Dignity Champion? (PLEASE SELECT ALL THAT APPLY)

Due to professional experience

Due to personal experience

Other (please specify):

What were your expectations of the role when you became a Dignity Champion?

To what extent do you feel that your expectations of the Dignity in Care Campaign have been met so far?

Not at all

Partly

Mostly

Completely

Don't know

What have been the main barriers you have faced in carrying out your role as Dignity Champion?

To what extent has the Dignity in Care Campaign helped to promote dignity in health and social care services in your local area, on a scale of 1-10, where 1 is 'hasn't helped at all' and 10 is 'helped a lot'? (PLEASE CIRCLE)

1 (Hasn't helped at all)	2	3	4	5	6	7	8	9	10 (Helped a lot)	Don't know
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If you could recommend one change to help improve the impact of the Dignity in Care Campaign, what would it be?

Are there any tools, guidance or information that, if you had access to them, would help you in your role as a Dignity Champion? If so, what are they? If no, leave blank.

## Leaders in health and social care survey

What is the nature of your role?

- Chief Executive
- Communications / Information / Technology
- Media / Marketing
- Commissioning
- Planning / Strategy / Business Development
- Finance
- Human Resources
- Other [please state]

What region do you work in?

- Yorkshire and Humber
- North East
- North West
- East Midlands
- East of England
- South East
- South West
- London

Are you aware of the Dignity in Care Campaign?

- Yes
- No

How engaged is your organisation in the Dignity in Care Campaign on a scale of 1-10, where 1 is 'not at all engaged' and 10 is 'very engaged'?

1 (Not at all engaged)	2	3	4	5	6	7	8	9	10 (Very engaged)	Don't know
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Are you aware of any Dignity Champions or Regional Leads working in your area?

- Yes
- No

Has the Dignity Campaign helped to promote dignity in care in your organisation, on a scale of 1-10 where 1 is 'hasn't helped at all' and 10 is 'helped a lot'?

1 (Hasn't helped at all)	2	3	4	5	6	7	8	9	10 (Helped a lot)	Don't know
-----------------------------	---	---	---	---	---	---	---	---	----------------------	------------

To what extent is dignity a priority at Board level in your organisation, on a scale of 1-10 where 1 is 'not a priority at all' and 10 is 'a very high priority'.

1 (Not a priority at all)	2	3	4	5	6	7	8	9	10 (A very high priority)	Don't know
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Are you aware of any procedures/indicators to measure dignity within your organisation?

- Yes
- No

What could the Dignity in Care Campaign do that would help you to engage in the Campaign and to champion dignity in your organisation?

Would you like to know more about the activities of the Dignity in Care Campaign?

Yes

No

(If answering 'yes' above): What would be your preferred method of communicating the activities of Dignity in Care Campaign with you?

Email bulletins

Publications

Conference

Workshops

Other [please state]

## 10.2 Interviews and engagement with key stakeholders

### Senior Thought Leaders discussion guide

#### Objectives:

- To capture views and definitions of the values and aims of the Campaign from those leading the way in dignity currently (whether within or outside of the Campaign) – why it was launched, what it is expected to achieve, its central values and tenets
- To explore perceptions of the Campaign to date – to what extent it has achieved according to the above definitions
- To gather suggestions for improvements in the future
- To gain insight into particular suggested areas of exploration for this Impact Assessment

#### Introduction

- **Introduce self and Opinion Leader,**
- **Explain purpose of interview** that speaking to them is just one stage in the research....
- **Reassurances:** Confidentiality absolute, no names used, no details / identifying factors passed onto anyone else
- **Recording:** check comfortable and also reassure don't have to answer anything don't feel comfortable with

#### Contextual information

- Title, job role, time in post?
- What **involvement / connection** do they have to the concept of furthering 'dignity' in general and to the Campaign in particular
- Gauge **how engaged** they are with the Campaign – maybe ask advocacy if appropriate ('to what extent would you describe yourself as an advocate of the Dignity in Care Campaign')
- How long have they been involved with / aware of the Campaign?

#### Values and aims

- Check how **familiar** they are with the aims of the Campaign
- How would they describe the **values and aims** of the Campaign (as far as they understand them)?
- What are their own **personal expectations** of what it will achieve? Any change in expectations over time or stayed the same?
- In terms of the aim to end intolerance of indignity in health and social care services - is there anything which in their view is **outside** of the remit of the Campaign?
- How would they **define dignity**? What are the main **indicators** in their opinion?

#### Views of the campaign (meeting these aims)

- What is their **opinion** of the Campaign to date?
  - Key successes
  - Weaknesses
- IF APPROPRIATE (i.e. person engaged in Campaign) What would they say has been the Campaign's main challenge?
- Bearing in mind the aims just discussed, to what extent do they believe it had met / exceeded / is yet to **meet it's objectives**?
- How would they rate the **impact** that the Campaign has had so far – why and what do they base this on?
- As far as they know is this impact
  - Local / national?
  - Consistent across the UK?
  - Across all areas of health and social care?
- Is it targeting the right people for maximum impact?

#### Suggestions for the future

- Given that the Campaign is coming up for it's third birthday in November this year, how do you see it's **future** beyond this?
- What would be your one piece of advice to those running it / **focus for improvement** beyond this date?
- Are there any **specific actions** that you believe would make a large difference to the impact the Campaign had?

#### Suggested areas of focus for the ongoing Impact Assessment

- As mentioned, the next and main stage of the Impact Assessment is to consult with those engaged in the Campaign – Regional Dignity leads and champions – this is our chance to find out what is happening in the Campaign on the ground ....
- We will be working up case studies of activity in areas in all of the 9 regions. Do you have any suggestions for **other people** that we should talk to in order to fully measure the Campaign's impact?

**Thanks and close.**

## Regional Dignity Lead discussion guide

### Objectives:

- To determine regional activity around the Dignity in Care campaign
- To capture their views/perceptions about the impact of the campaign regionally; what has been achieved; how; with who's help
- To collate information on local stories and case studies of initiatives being led by Dignity Champions
- To gather suggestions for improvements in the Campaign
- To organise subsequent site visits

### Introduction

- **Introduce self and Opinion Leader,**
- **Explain purpose of interview** that speaking to them is just one stage in the research....
- **Reassurances:** Confidentiality absolute, no names used, no details / identifying factors passed onto anyone else
- **Recording:** check comfortable and also reassure don't have to answer anything don't feel comfortable with

### Contextual information

- Ask respondent to describe job/role, organisation, time in post (probe on what they do as part of the Dignity in Care Campaign,)
- What was it that **attracted** them to the Dignity in Care campaign/Regional Dignity Lead role?
- What were their personal **expectations** of the Campaign/role? Have these changed since joining? If so, in what way?
- Ask them to describe how they have worked with local **Dignity Champions?** (i.e. leading from the front or letting them get on with it) and has their interaction been easy or difficult?
- *{For Regional Deputy Directors}* What **involvement / connection** do they have to the concept of furthering 'dignity' in general and to the Dignity in Care Campaign in particular

### Regional activity

- How have they implemented and embedded the **values and aims** of the Campaign in their region?
- What **areas / issues** have they focused on? Why? (differentiate between health and social care sectors)
- What kind of **changes / improvements** has the Campaign led to?

- Thinking about the top three changes or improvements they are most proud of, ask them to describe who has **helped** in achieving these? (Ask them to describe in turn the role of Champions, stakeholders, members of the public and DH)
- What are the main **indicators** that confirm that the changes have led to an improved focus on dignity for patients?
- What does the Campaign still need to be **address** at the regional level? Why hasn't this been tackled already?

#### Views of the campaign

- Ask them to describe the **overall impact** of the Campaign in the region? (number of Dignity Champions signed up, key successes and so on)
- What **impact** has the Campaign had so far – why and what do they base this on?
  - Key successes
  - Weaknesses
- Bearing in mind the aims of the Campaign, to what extent do they believe it has met / exceeded / is yet to meet its **objectives**?
- What has helped you to deliver the Campaign (probe on DH support advice, website, tools, networking, Regional Dignity Lead role and so on)?
- What hasn't helped you? (probe on DH support advice, website, tools, networking, Regional Dignity Lead role and so on)?
- As far as they know is this impact
  - Local / national?
  - Consistent across the UK?
  - Across all areas of health and social care?
- Is it targeting the **right people** for maximum impact?

#### Suggestions for the future

- What would they say is the Campaign's **main challenge** going forwards?
- Given that the Campaign is coming up for its third birthday in November this year, how do you see its **future** beyond this?
- Are there any **specific actions** that you believe would make a large difference to the impact the Campaign had?
- What would be your one piece of advice to those running it / **focus for improvement** beyond this date?

Suggested areas of focus for the ongoing review

- As mentioned, the next and main stage of the Review is to consult with those engaged in the Campaign i.e. Dignity Champions. Interacting with a cross section of the champion will be our chance to find out what is happening in the Campaign on the ground.
- We will be working up case studies of activity in different settings across the 9 regions. We would value if you could support us in this endeavour.
- At this stage, do you have any suggestions for the kind of stories / initiatives and the relevant Dignity Champions that we should talk to? Can you please provide me with names and contact details?
- We will also be conducting site visits to meet some of the Champions in order for us to conduct face-to-face interviews in each region. What advice can you give us for undertaking these visits in an effective manner?

**Thanks and close.**

## Dignity Champions case study discussion guide

### Objectives:

- To capture their views/perceptions about the impact of the campaign
- To collate information on their local stories and case studies of initiatives; what has been achieved; how; with who's help
- To gather suggestions for improvements in terms of role and campaign

### Introduction

- **Introduce self and Opinion Leader,**
- **Explain purpose of interview** that speaking to them is the most important stage in the research....
- **Reassurances:** Confidentiality absolute, no names used, no details / identifying factors passed onto anyone else
- **Recording:** check comfortable and also reassure don't have to answer anything don't feel comfortable with

### Contextual information

- Ask respondent to **describe job/role**, organisation, time in role
- Ask them to describe how they have worked with local **Regional Dignity Leads**: Probe on
  - How often they have contacted their RDL?
  - What have **contacted** them about? (i.e. asked them for advice and support only, depended on them for networking);
  - What areas do you most need **support** with?
  - Has the RDL been **helpful / unhelpful**? (And has their interaction been easy or difficult?);
  - Do you think it is important to have a Regional Dignity Lead? (Explain)
  - Any **recommendations** for RDLs in the future?

### Case study detail

- Ask them to describe their **case study/initiative** focusing on:
  - What is it?
  - Start date? End date?
  - The setting (i.e. care home, ward)
  - Who does it target?
  - What does it aim to achieve?
- From the following list of case study/initiative categories, which one does their's fall into:
  - *Incentive based initiatives* (staff awards; organisation awards; performance reviews)

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- *Awareness* Increasing initiatives (visuals; handouts; engaging staff, residents, community)
- *Staff support* (Additional specialised staff; increased resident/patient activities; encouraging volunteers)
- *Infrastructure* (Creating new activity areas, gardens; new gown design; creating new specialised wards)
- *Communication* (Establishing resident liaison; resident surveys; hearing amplification made available)
- *Training/Education* (workshops; courses; specialist teams; interest groups)

- What **areas / issues** did you focus on? Why? (differentiate between health and social care sectors)
- What **planning and preparation** did you do?
- Who else did you **involve**? (RDLs, patients an the public, voluntary organisations, other stakeholders, DH)

For each person mentioned ask if they would be interested in talking to us as well. If so, collect their name and contact details

- How did you **implement** it? What challenges did you face, if any?
- (If the initiative has finished ask): Why has the initiative been **stopped**?
- What kind of **changes / improvements** for patients, staff and others has their initiative led to?
- How has the patient experience been **improved**; specifically, what has been the affect on the dignity of the patient? What makes you say this?
- What **more** needs to be done?
- What kind of **indicators** have you used to measure these improvements?
- If you could do it all over again, what would you do **differently**? Why?

Inform participants about the 3 online focus groups; provide date and time. Seek their willingness to take part.

**Thanks and close.**

Case Study proforma

**Name:**

**Job Title:**

**Organisation / employer (if applicable):**

**Location:**

**Daytime telephone number (including area code):**

**The story I would like to share as part of the consultation is about..... (in less than 100 words)**

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**This is / was based in... (e.g. nursing home, hospital, etc...)**

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**Has the initiative / story involved other people locally? (e.g. voluntary organisations / professionals / colleagues. Patients themselves)**

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**Would you be prepared to ask others you have had contact with if they would also like to be involved in the research consultation? (Delete as appropriate)**

Yes
No

**Please describe below any initiatives you have been involved as part of the Dignity in Care Campaign and what they have sought to achieve:**

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**THANK YOU FOR YOUR TIME**