



HELP THE HOSPICES
COMMISSION

into the future of hospice care

Volunteers: vital to the future of hospice care

A working paper of the Commission
into the Future of Hospice Care

November 2012

In 2010 the think tank Demos published a report entitled 'Dying for Change' which highlighted some of the challenges facing hospices in the future. Help the Hospices responded to this by setting up the Commission into the Future of Hospice Care to provide guidance, information and options for hospices to inform their strategic position and offerings in the next 10 to 20 years. Opportunities exist across the UK to improve the experience of people who are approaching the end of their life, and that of their families and carers. The Commission is considering how hospices need to develop over the next three to five years to be prepared for the challenges facing them in the future.

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Foreword

Seven months ago, *The Commission into the Future of Hospice Care* hosted its first event at the Bishopsgate Institute in London.

Its title “Volunteers: vital to the future of hospice care” confirmed the belief of the Commission at its outset that volunteers will play an important role in ensuring the success of hospice care in the future. What was less clear to the Commission was how the contribution of volunteers can be most effectively deployed to meet the challenges facing hospices and others delivering hospice care.

To this end we organised a day calling on research evidence, expert opinion and the views of many individuals already engaged in the management of volunteers, as well as volunteers themselves, to help think about the future shape of hospice volunteering. The engagement of all involved was infectious and produced lots of ideas about how volunteering in hospices could be strengthened. On behalf of the Commission I am most grateful to all who participated.

We believe that the challenges facing hospices and other organisations engaged in end of life care in the future are considerable. The Commission is receiving reports that describe a strong likelihood of significantly increased demand for hospice care in 10-15 years time, from people with a whole variety of conditions, many of whom need care for prolonged periods and for whom care by families and friends may be limited. It is also hearing of an economic climate in which funding is increasingly limited and in which the quality of the workforce will become increasingly important. The effective use of empowered volunteers will be a significant part of how hospices respond to these challenges.

Work undertaken by the Commission to identify those principles that might best guide the work of hospices in the future confirms the importance of innovation, new partnerships, and increased work with the general public to help them make informed choices about end of life care. All these future actions would benefit from increased input from volunteers.

This report is a working document and as such one which we hope will provoke reflection and comment on the part of its readers so that we can refine it further. It represents our first thoughts about actions required on the part of hospices, national organisations including Help the Hospices and other stakeholders to promote high quality and effective volunteering in the future. We will be sharing the report widely, seeking feedback and further evidence to support or reshape the proposed recommendations.

I am delighted that it will be launched at the Help the Hospices conference in November 2012, as it reflects so clearly the conference theme of reciprocal community engagement. This is a vital role for volunteers and important for the future of hospices.

I hope you enjoy reading it and look forward to hearing your thoughts and comments.

Dame Barbara Monroe

Executive summary

This is a working paper of the Commission into the Future of Hospice Care. Its intention is to share our ideas and early recommendations. It is a starting point for further discussion and debate before the Commission presents its findings and final recommendations in the autumn of 2013.

The paper draws upon presentations and discussions at a participative conference held by the Commission in April 2012. At this event we gathered together academics, volunteers, volunteer managers, those with experience of using volunteers across a range of settings and those with international experience to discuss and debate the role of hospice volunteers in the future (The Commission 2012).

This working paper is rooted in rigorous debate about the role of volunteers. It is not a summary of the available evidence base although it draws on research findings presented in the course of the day. Indeed, the evidence base for considering the potential future role of volunteers is sparse although we recommend the work led by Sara Morris at the International Observatory on End of Life Care for a current review (Morris 2012).

The paper makes the case for a range of ideas concerning the possible future development of volunteers. We hope that it will challenge and provoke you, and that you will join with us over the next nine months in testing the strength of these ideas. We ask for your help in providing examples that might illustrate those approaches to volunteering that you feel are most important for future development.

All of our analysis and our proposals are based upon the premise that volunteers are vital to the high quality experience of those who seek help from hospices and that in return hospices can offer volunteers a rewarding and life enhancing experience.

Our thinking and our proposals for action are presented under the following three headings:

- Building on existing best practice;
- Promoting excellence in the future; and
- Exploring new approaches to volunteering.

We also make five key recommendations about the future of hospices volunteering that we believe further strengthens the contribution of volunteers as well as their experience of volunteering and which will enable the development of hospice care in a way that meets the foreseeable challenges of the future.

Building on existing best practice

As hospices adapt to the growing demand for care we believe that there is a strong case for:

- Thinking of volunteers as essential to any hospice strategy for extending reach and impact;
- Growing the recruitment of a larger volunteer workforce;
- Supporting hospices to do more, enabling a more effective and extensive deployment of volunteers; and
- Working to agree and develop packages of volunteer training that can be adapted and applied locally.

As the volunteer contribution becomes more significant we also see a need to:

- **Identify clear boundaries for the volunteer** working in a patient-facing role;
- **Ensure the common application of approaches** that sustain safe volunteer practice;
- **Ensure procedures for safeguarding patients** and volunteers; and
- **Extend the effective supervision of volunteers** in patient-facing roles.

To achieve this extension of best practice we make two recommendations:

1. Hospices and the national organisations representing hospices and hospice care should work together to publicly promote the value of hospice volunteering with a commitment to recruit a new wave of hospice volunteers.
2. That hospices and their national organisations take the next step in extending the contribution of volunteers by establishing and evaluating training packages for local use; for establishing agreed guidance on the boundaries of volunteer practice; and collating, publishing and promoting existing effective innovation in hospice volunteering.

Promoting excellence in the future

In looking to the future, the Commission believes the volunteer contribution can be further extended to help hospices meet a growing demand for hospice care.

We believe that there is a strong case for hospices and national hospice organisations to invest in volunteering, volunteers and voluntary management so that volunteers might contribute more.

3. Our third recommendation is that Help the Hospices take the lead on a significant programme to support the development of innovative and evaluated models of practice. Such innovation should be focused on three areas:
 - i) Enabling volunteers to play a full role in the work of the clinical team within and beyond the walls of the hospice, serving as an integral aspect of this team and working in partnership with clinical colleagues;
 - ii) Making the most of volunteers (including trustees) as significant contributors to the innovation of services and the shaping of hospice strategy. This recognises the volunteer as a potentially vital connection between the hospice and those communities it seeks to serve; and
 - iii) Considering new approaches to sustaining, maintaining and nurturing the volunteer contribution through better volunteer stewardship. The hospice volunteer may be as valuable to the organisation as a financial donor or clinical professional.

Exploring new approaches to volunteering

The Commission maintains a strong focus on how hospices and other providers of hospice care may adapt and prepare for the substantial challenges of a future characterised by changed demography and disease and a greater demand for more complex and prolonged care towards the end of life.

In considering how hospices prepare for such challenges we believe the ability to organise the volunteer contribution is key. We encourage hospices to experiment with ways in which volunteers might play a role, whilst seeking to evaluate, research and learn so that these experiments are useful to us all.

We believe that there are two areas where considering radically new approaches may hold real promise.

4. Our fourth recommendation is that hospices and national organisations representing hospices test more radical adaptations to current volunteering practice, specifically:
 - i) Exploring the encouragement of new organisational forms for hospice-owned but volunteer-led volunteer services at the end of life. We believe this may enable volunteers to be organised in ways that support them to contribute across a range of end of life care providers bringing knowledge and continuity to a system of care that is all too often fragmented; and

- ii) Enabling volunteers to take on significant roles in helping people (and their families and carers) understand, navigate and even play a part in co-ordinating the pattern of care often delivered by many providers who may need to be part of someone's life for significant stretches of time.
5. This desire to develop, extend and enhance our understanding informs our fifth and final recommendation – that hospices and their national organisations shape a call for more extensive research in hospice volunteering, building an evidence base concerning the effectiveness and economic impact of volunteer-led, volunteer-delivered or volunteer-enabled end of life care innovation.

Finally

We hope our ideas, proposals and emerging recommendations are engaging. Our intention is that this working paper should be useful for trustees, staff and others helping hospices plan for the future. We invite you to help us develop this early thinking by contacting the Commission and giving feedback. Comments, ideas and challenge are welcomed. We are keen to listen.

Introduction

Volunteers will be vital to the future of UK Hospices and the UK Hospice movement.

Volunteers sit on the boards of hospices, work in most hospice buildings and increasingly are becoming the routine presence of the hospice across the communities that it serves. Volunteers are extending the hospice ethos to larger numbers of people living with life shortening illness and the volunteer is already at the frontline of enabling hospices to meet the challenges of an aging population.

On the 20th of April 2012 the Commission into the Future of Hospice Care ran a participative conference to explore the contribution that volunteers might make in enabling hospices to meet the challenge of providing care for larger numbers of people living with progressive and incurable disease.

This is one of the first Commission working papers and it arises from the evidence gathered and the thinking shared at that event. We publish it as a working paper to enable you to respond to our ideas and our draft recommendations and to contribute to our thinking. We are keen that this paper stimulates further thinking and debate which can help inform the final recommendations from the Commission. More about the work of the Commission as well as ways to contact us can be found on our website at www.helpthehospices.org.uk/commission.

The paper is a summary of our analysis, our thinking and our draft recommendations for this vital area of future development for hospices. In considering the future of hospice care we are concerned to address not only the care that is provided by hospices but also the way in which hospices may work with others to influence, support and sustain care at the end of life across a range of current and future settings.

Our analysis and our recommendations are grouped under three headings:

- A. Building on existing best practice;
- B. Promoting excellence in the future; and
- C. Exploring new approaches to volunteering.

At each stage we will highlight our emerging proposals for hospices, for national membership and umbrella organisations and those organisations with influence on the social and health care system within which hospices operate.

We believe that it is important to start by recognising volunteers as a significant strategic advantage for hospices. We believe that:

- **Volunteers extend the skills and the scale of** the human resources available for a broader range of services delivered by both paid and unpaid workers. They offer a sustained caring connection to people with life shortening illness, in all settings and in ways that transcend the purely clinical.
- **Volunteers enable hospices to extend their reach** and their ethos through a wider range of social and well as clinical activities both in the hospice and across the communities they serve.
- **A diverse volunteer network brings the benefits** of a broader range of skills, expertise and knowledge to hospice care providers and can help take these organisation and their services out to a similarly broad range of diverse communities.

We urge hospices, their representative organisations and those with influence in the health and social care world to acknowledge the value of volunteering in hospice care as a means of developing and improving care at the end of life.

A. Building on existing best practice

1. Growing volunteer recruitment

The latest research presented to the Commission by the Institute of Volunteering Research (IVR) was conducted in 2011 and establishes, on a return from 67% of adult hospices and palliative care units, that the mean number of volunteers per hospice was 240 (Hill 2012).

If this were replicated for all hospices it would suggest a UK volunteer workforce of approximately 70,000. This is a significant resource. However, similar work undertaken by Help the Hospices in 2006 estimated the size of the UK volunteer contribution at 100,000 (Help the Hospices, 2006).

Of this volunteer workforce half had direct contact with hospice patients and their families. In presenting early findings to the Commission the IVR commented that hospices “hadn’t found it hard to recruit volunteers to roles that involved direct patient contact”. We suggest that despite the apparent difficulty of such roles, providing meaningful care and support to the dying has an enduring appeal to hospice volunteers.

The Commission believes that the current interest in volunteering more generally and the role that volunteering may play in enhancing people’s prospects at a time of high unemployment means that there is a significant opportunity to attract and deploy a larger volunteer workforce.

We suggest that hospices constantly seek to bring new volunteers to their organisation. There is growing organisational competition for volunteers and the hospice approach to recruitment, training, management and stewardship must be tailored to meet the needs and motivations of future volunteers.

- We propose that hospices partner with national organisations to launch a national public recruitment drive for volunteers.
- We propose that this campaign is supported by a national website where individuals can register interest and receive information.

2. Agreeing common training

When it comes to the training of hospice volunteers, different hospices take different approaches.

This lack of common approach isn’t solely a practical matter concerning the lack consensus for a common curriculum or a lack of consistent structures and dedicated resources. There is a deeper disagreement as to the appropriateness of volunteer training.

Some hospices take the view that the value of a volunteer workforce comes from their ability to bring an approach to the work that is not modified by the professional socialisation that can come with training. Some hospices wish to argue that training itself, if it is too extensive, may risk undermining the added value that the volunteer brings.

However, the Commission believes that high quality training can avoid the inappropriate professionalisation of the volunteer. Indeed, good training can help the volunteer manage the boundary between the professional approaches to care and their contribution to the team. Some hospices argue that such training can facilitate the ability of the volunteer to understand, value and enhance their unique contribution to the care of the patient with a confidence that might otherwise be eroded in practice.

It is our view that the case for a substantial training programme to assist volunteers to bring their perspective, skills and humanity to the care of the patient, is strong. We hope to persuade others of the strength of this case. In our view training should focus on enabling the patient-facing volunteer to:

- **Recognise the considerable positive impact of the volunteers presence in the caring relationship;**
- **Develop an appreciation and understanding of the contribution that being with the patient and the family can bring;**
- **Gain an understanding of the way in which accompanying the patient and family at such a difficult time can help them with the inevitable making sense of their situation that has to occur at such difficult times;**
- **Develop an appreciation of their ability to use their contribution to also release professionals to dedicate more time to good communications and patient engagement;**
- **Manage the emotional workload of working in the presence of potential distress, difficulty and existential questioning;**
- **Understand the difficult practical challenges of good practice in relation to health and safety and the regulatory obligations that come with good care;**
- **Ensure the volunteer understands and can react appropriately when there are possible issues concerning the safeguarding of vulnerable people; and**
- **Enable the volunteer to manage the subtle tasks of hosting, managing and tailoring the hospice environment and shaping the organisation's resources to the patient needs.**

We believe that such training could enhance and enable the personal contribution of the volunteer working in patient-facing roles and even sustain and support their ongoing commitment to the work; as well as prolonging their engagement in the volunteering role.

Many hospices consider this approach to be important but are not always able to manage the significant tasks of organising, planning, delivering, and evaluating such training programmes.

- **We propose that hospices invest in volunteer training that equips volunteers with the knowledge to effectively use their skills and experience to give care in all that they do and to always represent the values of their hospice in every act.**
- **We propose that membership bodies for hospices commission an educational provider to design the core components of a training programme with a view to making these available to hospices as part of local training programmes.**

We believe that this core educational package be designed to enable volunteers to work effectively and safely in patient-facing roles, covering issues such as: ensuring safe-working and the safeguarding of patients and volunteers, maintaining healthy and effective boundaries of care; and identifying the responsibilities of working with a clinical team.

We also suggest that a national evaluation of these training components be commissioned; assessing their effectiveness for hospices, volunteers and the subsequent delivery of safe and valued practice.

3. Sustaining safe practice

Evidence presented to the Commission demonstrated that many hospices were at best wary and at worst reluctant to find ways in which to enable volunteers to provide direct care to patients because of real or perceived restrictions upon practice arising from national regulations. Hospices were concerned that such regulations could hamper the ability of the volunteer to undertake tasks that, paradoxically, might be undertaken by a neighbour, relative or friend.

We believe that in the absence of clear guidance on the application of a range of regulatory rules from organisations such as the Care Quality Commission, many hospices are taking a conservative approach to the difficult judgement of how to define the role of the volunteer, especially when befriending or working with those who are vulnerable. In our view, it cannot be right that volunteers are advised that it would be counter to health and safety regulations to make a cup of tea in someone else's home. Nor can it be correct that volunteers are advised not to help with someone with feeding by wiping someone's lips with a napkin after they have eaten. Both of these examples have been shared with the Commission.

Given that a range of regulatory frameworks may deliberately or accidentally apply to a range of volunteers working to support vulnerable people in a host of different settings, we suggest that national membership bodies work with Volunteering England and similar bodies across the UK to jointly establish a dialogue with the Care Quality Commission and other national regulatory bodies who may be perceived to be creating rules that might inhibit the work of the volunteer in the future. Clarity and communication are important if the current set of beliefs concerning the perceived restrictions on a range of different authorities are to be effectively managed.

- We propose that this dialogue leads to published guidance setting out the boundaries of acceptable practice for volunteers. This guidance should be reviewed annually and made available on the websites of Help the Hospices, Together for Short Lives, Volunteering England, the Care Quality Commission and equivalent bodies across the UK.
- We propose that membership organisations consult with their members over the relative merits of national standards for volunteers working in patient-facing roles. The evaluation of training for volunteers should consider whether a core educational package could lead to the development of an effective system of self-regulation for the volunteer workforce.

An additional aspect of safety that was pressed on the Commission concerned the need to ensure volunteers are trained and supported sufficiently to manage issues of safeguarding. This was considered a significant issue, both in terms of volunteers being able to manage concerns as to the welfare of patients and hospices being able to ensure that volunteers were themselves supported in the face of the emotional and practical difficulties of the work. We are struck by the evidence of the most recent hospice survey that shows 35% of hospices are without policies for volunteer supervision (Hill 2012).

We believe hospices should provide clear guidance and support for volunteers who deliver care or support to users of their services: covering issues such as appropriate safeguarding for patients and the management of personal boundaries. In addition they must consider the provision of support and mandatory supervision to help volunteers manage the inevitable emotional workload that comes with sustained closeness to death and dying.

4. Effective volunteer deployment

The strategic challenges for many hospices lie in enabling access to hospice services for all who need and could benefit from it, and in developing cost effective models of care particularly in the community. The use of volunteers is a significant part of responding to these challenges.

Volunteers can play a significant role by directly contributing to the effective management of care in the home supporting patients and families as part of the community team. Volunteers can also extend care within the hospice setting so enabling a more effective deployment of professional resources in the hospice and the community. But whatever the varied opportunities and the benefits they can bring, the current use of the volunteer resource is uneven.

Research conducted by the Marie Curie Palliative Care Research Unit at University College London suggests that 68% of respondent hospices are not using volunteers in home care; 44% of respondent hospices are not using volunteers in outpatients; and a quarter are not using volunteers in inpatient services (Candy 2012). In addition, where volunteers are being used to enable or deliver services either within the hospice or in the community we find that the volunteer is often not integrated into the work of the clinical team.

- We propose that national hospice organisations work with other national organisations to publish and promote a report describing effective and innovative practice in the use of hospice volunteers working in patient-facing roles across community and inpatient hospice services. This should seek to highlight different models of practice for integrating volunteers working in such roles with the hospice clinical teams.

5. Extending the reach of hospices and their volunteers

The Commission has been given compelling evidence of a lack of congruence between the make up of the communities served by individual hospices and the composition of their volunteer workforce. We believe that this inhibits the ability of a hospice to use its volunteer workforce to establish a presence and build an understanding of the hospice in the many communities that it serves. We also believe that it denies hospices the opportunity to use volunteers effectively to ensure the delivery of personalised care, particularly for patients and families who come from minority communities and may present with needs and preferences with which many staff may not be familiar.

In the sharing of early findings from the Institute of Volunteering Research we were told that hospices struggled with getting a representative range of people through the door. For example, in terms of gender 77% of the volunteers encompassed by their 2011 survey of all UK hospices were female and similar disparities were evident in relation to the representation of different ethnic groups in the volunteer workforce (Hill 2012).

However, the Commission also heard convincing testimony that by using alternative and more formal approaches to recruitment (most hospices relied on 'word of mouth' to recruit and refresh their volunteer body) and by offering formal training (meeting the needs and anxieties of a more diverse potential volunteer workforce), it was possible to attract a different cohort of volunteers. One hospice used such an approach to recruit a volunteer intake where 37% of the volunteers were under the age of 40; 40% volunteers male; and 28% from the black and minority ethnic communities that they served (Hartley 2012).

- Hospices should aim to secure the benefits of the broadest range of skills and expertise in their volunteer workforce and should explore the use of a wider range of approaches to recruitment, engagement and training in order to achieve this objective.

B. Promoting excellence in the future

6. Investing in volunteer management

One question that arises from considering international practice in volunteering at the end of life concerns the relative UK investment in volunteer management.

In Austria the model used involves two volunteer co-ordinators (undertaking a range of tasks that broadly have some similarity with volunteer managers in the UK) working with a team of between 20-25 volunteers. We acknowledge that in many respects the approach is different with the co-ordinator helping to run the volunteer organisation outside of any hosting organisation and playing a role in organising the delivery of over 120 sessions of training for new recruits (Pelttari 2012).

However, applying the equivalent ratio of volunteer co-ordinators to volunteers in a UK context would mean approximately 3000 UK volunteer co-ordinators or managers. In fact the UK hospice movement probably employs less than 1/10th of that number of people with a specific volunteer-facing management or coordination role.

This comparative underinvestment may help explain why 60% of UK hospices cited time, and 40% funding, as 'very important' barriers to effective volunteer management. It may also be a consequence of what 40% of volunteer managers saw as a lack of support from the governance of the hospice when it came to effectively undertaking their work (Hill 2012).

We believe that hospices should consider volunteers to be as valuable to the organisation as any other member of the hospice staff. Hospices should recognise that volunteers therefore require the same investment in effective management as other staff groups so that they are best able to deliver the organisation's goals and vision.

- We propose that Help the Hospices lead the development of a major programme of development, focused on promoting innovation and good practice in hospice volunteering. Such a programme would provide a systematic approach to funding, developing, testing and evaluating innovation related to volunteering in hospice care.
- We specifically propose that through this programme, hospices be encouraged to adopt, adapt and develop new models of both paid and unpaid volunteer management.

7. Enabling volunteers in professional teams

The Commission has heard examples of where the professional boundary between health care worker and volunteer has either inhibited clarity over respective caring roles or led to difficulties in making the most of the whole team involved in care. Some clinical professionals have felt threatened by the volunteer contribution and some volunteers have felt marginalised from the multi-disciplinary team management of those at the end of their lives.

There is a need for a better mutual understanding of roles and responsibilities, something that can be taken forward in the training recommendations. However, this is just the start. Hospices must learn from each other about how to integrate the volunteer contribution to care into the systems of clinical management and clinical governance in ways that respect the different skills and perspectives of all involved.

The Commission acknowledges concerns that expanding the volunteer workforce may threaten paid jobs within individual hospices or across the sector. Our starting point is that a hospice must be committed to constantly identifying the most effective mix of specialist, generalist and volunteer contributions to care. Developing volunteers may well require hospices to re-visit the structure of paid work in the hospice.

In an increasingly competitive world, hospices should not be shy of looking to use the economic and staffing advantages of a capable volunteer workforce. After all, the ability of the hospice to attract and deploy the voluntary contribution may sustain the hospice and enable growth that includes the increased development and deployment of a highly professional paid workforce.

To survive, hospices will need to adapt to demands to undertake care for a broader population of people with a wider range of needs. Part of this adaptation will be to consider the strategic use of the volunteer contribution to services that may need to reach out to people living with single or multiple chronic illnesses that are progressive and incurable but also unpredictable in course. Volunteers may offer advantages here in the development of systems of care that support people through sustained periods of ill health prior to death.

The Commission believes that as hospices adapt to ensure their offers of care fit the changing demography and illness profile of the population, they will need to consider a changing workforce to meet changing needs. We suggest that hospices give particular consideration to how they meet the needs of increasing numbers of people living with chronic illness, particularly that which is neurodegenerative in nature, such as dementia.

We suspect that this may require hospices to consider the use of volunteers beyond the hospice, as a part of a broader team spanning a variety of health and social care organisations where

professional expertise is provided more sporadically in response to changing needs and where the volunteer helps provide the continuity between those episodes that require a professional response.

We are aware that adopting this model may challenge some existing professional approaches. Such a shift may challenge the health care professionals' notions of accountability and 'ownership' of patients and require more flexible concepts where the volunteer presence in the community may be a vital component of continuity.

We suggest that hospices need to consider openly the configuration of paid workers and un-paid volunteers to ensure the best use of financial resources as well as the best deployment of skills and talents to the utmost benefit of the hospice users.

- **We propose hospices bring innovative thinking** to ensure that the volunteer contribution can be integrated with the work of the full range of clinical and non-clinical teams across the organisation.
- **We propose that the newly proposed hospice** volunteer development and innovation programme identify and support innovative models of care that properly integrate the volunteer into the multi-disciplinary team, and related systems to support hospice inpatient and community patients.

8. Ensuring good volunteer stewardship

There is a lack of consistency in the way hospices nurture the volunteer and attend to a proactive management of the volunteer's journey through the organisation. Similarly, there is highly variable practice when it comes to sustaining the volunteers' development and re-invigorating the volunteers' motivation and commitment.

The Commission is aware of growing competition between voluntary and community organisations to tap into the resources of the volunteer. At our event in April 2012, we heard from new social enterprises

creatively using the resources of volunteers in the community to establish a range of new services. We suspect that potential volunteers have a widening range of choices when it comes to choosing a volunteer-hosting organisation that matches their expectations and motivations.

We believe hospices will need information to help them consider the changing motivations for volunteering (many of which may be influenced by age and career stage or aspiration). Hospices will need to more routinely consider the volunteer's journey through their organisation and to consider how to widen the range of options for volunteer development.

Good data will be essential if hospices are to map and match volunteering opportunities to the changing motivations, experiences and expectations of the volunteering workforce itself. We are also struck by the lack of data on broader issues of volunteer management such as the rate of return for investment in volunteer recruitment, training and management or the potential conversion of volunteers either 'into' or 'from' the pool of hospice specific committed givers.

Hospices will need to improve the way they foster, care and nurture the volunteer workforce: adopting more sophisticated approaches that mirror the concern of fundraisers and chief executives to ensuring effective stewardship for their donors. We believe this data will become central to hospice management and work should begin now to start to understand the appropriate approach and parameters that might guide the collection, understanding and use of such data.

We believe that a hospice volunteer may be as valuable to the organisation as a financial donor or clinical professional and that hospices should recognise this through an effective stewardship of the volunteer relationship.

- We propose that the hospice volunteer development and innovation programme be used to support the identification of effective performance measures for monitoring the stewardship of volunteers: establishing a benchmarking group committed to using and sharing common measures such as volunteer turn-over and retention rates: and using the work to produce guidance on good practice in hospice volunteer stewardship.

9. Unlocking innovative potential

Bringing the varied experiences of volunteers into the heart of the hospice is one way of creating the right organisational environment for innovation. We believe that such innovation might enable the hospice movement to rise to the challenge of delivering the quality and intimacy of care for which it is renowned, on a new scale, to a wider population with different needs, all in a changing commissioning environment.

Yet the evidence tells us that only 33% of hospices are giving volunteers 'representation' in the formal organisational structures of the organisation (Hill 2012). Volunteers bring a different perspective to an understanding of what the hospice can achieve. Crucially this perspective is offered by someone from a community that the organisation hopes to serve. It may well be rich – drawing on the experience of being an informal carer, or informed by the perspective of a family member who received hospice care.

The volunteer's perspective as an 'outsider' with an insider's influence may be vital to invigorate innovative thinking. The low rate of volunteer engagement in this kind of strategic exploration is a missed opportunity for the hospice and the hospice sector generally.

We believe that a diverse volunteer network offers the hospice valuable experience and knowledge that is relevant to the innovation of their services, in order that they might better match the needs and circumstances of people in the communities they wish to serve.

- We suggest that the newly proposed hospice volunteer development and innovation programme is used to help hospices identify mechanisms for recognising and enabling those volunteers (including trustees) with an established connection to past, current or possible service users, to become part of a deliberate hospice programme for the innovative development of new services.

10. Enabling effective strategic contribution

Volunteers have an important contribution to make to the development of hospice strategy. More could be done to enable this to happen.

The value of volunteers, including hospice trustees, in developing strategy is rooted not only in the personal skills, attributes and insights of the individuals. It also rests in their ability to bring representation or connection to those communities under-represented in hospice users; to people who have been or could be cared for by the hospice; or the networks necessary to create new partnerships within the locality.

Volunteers offer the vibrancy of new perspectives to the development of strategic direction within a hospice. However it is right that hospices also ensure that the volunteer contribution to strategic direction is rooted in demonstrable real world connections. Too often organisations find setting the conditions for engagement too difficult and thereby miss out on the significant advantages.

- We propose that hospices seek to benefit from the significant connections that volunteers (including trustees) can bring to their organisation and enable their engagement with questions of strategy. However, we believe that the input of volunteers should be matched by their demonstrable connection to the wider public particularly those under represented communities whose voices are vital to the development of good strategy.
- We propose that the newly proposed hospice volunteer development and innovation fund be used to support the development of hospice programmes that explicitly engage volunteers in strategy development. A significant proportion of these volunteers (including trustees) should have an established connection to those communities who are under-represented as users of the hospice and any approach tested should be easily replicable.

C. Exploring new approaches to volunteering

11. Encouraging new organisational structures and cultures

Volunteers are commonly managed as part of the traditional hospice management structure. Although their contribution may extend across all that the hospice does, their voice in the innovation of care or the development of strategy may not be strong.

Volunteers are attracted to particular hospices because of their connection to the institution and its values. However, hospices sometimes struggle with adopting organisational attitudes and structures that might enable volunteers to feel as valued and as integral a part of the hospice team, as they might like.

Working outside of a conventional contract of employment, the agreement between the volunteer and the organisation is based on mutual respect. The value the volunteer perceives the organisation placing on their contribution is important, as is the hospice's perception of the volunteer's reciprocal requirement to value and engage in the organisation's purpose. Such a relationship can be quickly threatened by disengagement between organisation and volunteer.

We believe it is worth hospices considering the development of new hospice-owned but volunteer-led forms of organisations that might positively change the structures and attitudes that in some cases can restrict volunteer impact. These might take the form of new hospice based social enterprises or community interest companies – in effect hospice supported 'volunteer chambers'.

Such organisations could enable the hospice to develop partnerships with a range of other local volunteer organisations and work to deliver the hospice ethos as well as the hospice based volunteer service into end of life care delivered by a range of other providers across the local economy. Such organisations might find it easier to sustain and support the volunteer commitment, offer more opportunities for development and more varied options to develop the volunteer journey.

- We propose that hospices review the strategic opportunities for new partnerships and organisational structures through which they can develop, sustain and deliver the volunteer contribution. We suggest that they seek to use such new structures to deepen the volunteer connection to the hospice while also extending hospice care through a wider deployment of the volunteer workforce.
- We suggest that the newly proposed hospice volunteer development and innovation programme be used to encourage hospices to set up new forms of organisation for their volunteer services. These new organisations would be hospice-owned and developed with the explicit intent of delivering volunteer services beyond the hospice across a range of providers supporting people at the end of life.

12. Working across care systems

The future commissioning of care for those at the end of life is likely to emphasise the role of end of life care organisations (sometimes hospices) in providing a named individual who can manage or co-ordinate care from across a range of providers. This is designed to achieve greater consistency in care across organisational boundaries and potentially allows the ethos of hospice care to be extended beyond care delivered directly by hospices.

However, achieving this consistency across a range of providers with various workforces who are managing different facets of the patients care will be difficult. The Commission believes that hospices may wish to consider new roles for volunteers in working with clinical staff to help bridge these differences. In this role volunteers might aim to generate a shared knowledge of hospice care and work towards ensuring that care was delivered with continuity and consistency across multiple providers.

This type of role could significantly develop the contribution of the volunteer, opening up the potential for volunteers to work as potential navigators, co-ordinators or advisors in relation to the whole system of care, working with those being cared for or their families to ensure that their wishes and concerns are at the heart of what happens. In the future volunteers in this role may even advise on the application of personal budgets.

- **We propose hospices consider the role** that volunteers may play in enabling the co-ordination of end of life care across a range of providers. There is much to be learnt about how such a radical new role for volunteers might work and a robust evaluation of their impact would be vital to inform hospices about the value of this type of contribution.
- **We propose that the proposed development and innovation fund** be used to enable hospices to develop and evaluate new roles for hospice volunteers as coordinators, advisors or navigators of care. Volunteers in these roles would work closely with the person being cared for and their families to put their concerns and wishes at the heart of care often provided by multiple providers.

13. Deepening understanding

The Commission is struck by the way in which the current evidence base for hospice volunteering is focused predominantly on basic questions concerning numbers and roles. There are significant gaps in the knowledge required to enable hospices to understand the future potential of the volunteer in this unique and difficult area of care. Particularly noticeable is the lack of work that takes the perspective either of the volunteer or the direct recipient of the volunteer contribution.

Innovation flows from good ideas in practice. We suggest hospices engage in programmes of service development that use volunteers in new and extended roles; that build the confidence of

volunteers and promote the value of volunteer-delivered or volunteer-enabled services. These programmes should be evaluated where possible and shared widely to enable others to add to the critical mass of new practice.

- **We propose that hospices identify priorities** for research that might enable a greater understanding of the potential future roles of volunteers working at the end of life. This research should encompass the experience of the volunteer and the patient and family who experience the volunteer contribution. Hospices should establish partnerships with research institutions, in collaboration with other hospices where possible, to bring such research into their organisations. They are also encouraged to engage with volunteers to design and undertake the research.
- **We strongly suggest investment at national level** in programmes of evaluation around innovative models of volunteering in hospices. This will help the sector better understand a range of innovative practice to integrate volunteers into clinical care; to identify the conditions that enable volunteers to effectively contribute to strategy and innovation; to enable good practice around volunteer stewardship; to establish new forms of volunteer organisation with a reach across the whole system of end of life care; and to explore the value of new navigator roles for volunteers working at the end of life.
- **We propose national hospice organisations** engage with the UK End of Life Care Research Interest Group with a view to promoting research that will help build an evidence base concerning the effectiveness and economic impact of volunteer-led, volunteer-delivered or volunteer-enabled end of life care innovation. This research should explicitly encompass the experience of the volunteer as well as the patient and family who experience the volunteer contribution.

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Acknowledgements

The Commission into the Future of Hospice Care are indebted to the many participants; speakers and facilitators who participated in our conference on the potential contribution of volunteering to hospice care in the future (Commission 2012).

In particular those who contributed their expertise to chairing the day and adding insight to the Commission's expert panel: Baroness Julia Neuberger DBE, West London Synagogue; Professor Sheila Payne, International Observatory on End of Life Care and Help the Hospices Chair in Hospice Studies, University of Lancaster; Mike Locke, Volunteering England; and David Pastor, Chief Executive of Claire House Hospice.

We would like to thank all those who were prepared to share their experience and their evidence with the Commission and put their analysis of current volunteering practice and the challenges of the future up for scrutiny. They are: Matthew Hill, Institute of Volunteering Research; Bridget Candy, University College London; Leena Pelttari-Stachl, Hospice Austria; Steven Howlett, University of Roehampton; Dr Libby Sallnow, St Joseph's Hospice; Ivo Gormley, Good Gym; Barbara Gale, St Nicholas Hospice; Patricia Somerset, Alzheimer's Society; Nigel Hartley, St Christopher's Hospice; Rosalind Oakley, Cass Centre for Charity Effectiveness; Gerry Mahaffrey, Trustee, St Joseph's Hospice; Guy Patterson, Age UK; and Ruth Bravery, Marie Curie Cancer Care.

This working paper has been written by Steve Dewar, Consultant to the Commission, working closely with the rest of the Commission Support Team. Finally, our thanks go to those who gave their time to comment on earlier drafts of the report, specifically Ros Scott, Director of Organisational Development, Children's Hospice Association Scotland; and Richard Carling, Director of Finance and Resources at Together for Short Lives, who both sat on a Commission Sounding Board Group for Volunteering that influenced our early ideas. Significant contributions to the report were also made by Dr Heather Richardson, Executive Lead for the Commission; Dame Barbara Monroe, Vice Chair of the Commission; and Harry Cayton, Chief Executive of the Professional Standards Authority for Healthcare Regulatory Excellence and Commission member; the final report was also helpfully reviewed by all other Commission members.

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