

# HEALTH AND WELLBEING BOARD PAPER FORMAL PUBLIC MEETING

Report of:	Greg Fell, Director of Public Health, SCC
Date:	29 <sup>th</sup> September 2022
Subject:	Progress towards becoming an intelligence-led, Compassionate Sheffield
Author of Report:	Eleanor Rutter – Consultant in Public Health

# **Summary:**

This paper sets out for the Health and Wellbeing Board the progress made in relation to 'Compassionate Sheffield' and taking an intelligence-led approach to it. Detailed information regarding specific projects is included in the paper which ends by asking the board for ongoing support including financial resource which it is recommended they ask the Sheffield Joint Commissioning Committee to take this forward as part of Sheffield's programme of integrated commissioning.

# **Questions for the Health and Wellbeing Board:**

- We ask the board to note the work that has been done in a relatively short period and challenging circumstances. Does the board agree that this work is an important foundation to achieve the ninth ambition of the H&WBS and as such, does it sponsor its continuation?
- Will the board agree to receive further updates in due course after a period of sustainable funding?
- Can board members refresh individual organisational commitment to the integrated intelligence approach?

# Recommendations for the Health and Wellbeing Board:

 We recommend that the H&WB board asks the Sheffield Joint Commissioning Committee if they will take this work forward as part of Sheffield's programme of integrated commissioning.

# **Background Papers:**

https://democracy.sheffield.gov.uk/documents/s36621/Item%204%20-%20End%20of%20Life.pdf

# Which of the ambitions in the Health & Wellbeing Strategy does this help to deliver?

Ambition 9: Everyone in Sheffield should live the end of their life with dignity and in a place of their choice.

## Who has contributed to this paper?

Sam Kyeremateng – Consultant in Palliative Care and Medical Director, St Luke's Hospice Nick Deayton – Programme Manager, Compassionate Sheffield Chris Gibbons – Public Health Principle

# Progress towards becoming an intelligence-led, Compassionate Sheffield

## 1.0 SUMMARY

This paper sets out for the Health and Wellbeing Board the progress made in relation to 'Compassionate Sheffield' and taking an intelligence-led approach to it. Both projects suffered significant delays, due to loss of staff leadership capacity during the pandemic, but both have also made significant progress. Detailed information regarding specific projects is included in the paper which ends by asking the board for ongoing support including financial resource which it is recommended they ask the Sheffield Joint Commissioning Committee to take this forward as part of Sheffield's programme of integrated commissioning.

## 2.0 HOW DOES THIS IMPACT ON HEALTH INEQUALITIES IN SHEFFIELD?

A good end-of-life experience is said to be one where all physical, social, psychological and spiritual needs are met. Sadly, not everybody can expect to have their needs met optimally by the current system in Sheffield. By gathering stories in communities and marrying those up with quantitative data sets we can have a better understanding of who is having a good experience and who is not. By working first in communities least likely to have the best experiences and helping people to learn to use compassionate language and finding the confidence to offer, and to ask for help, we can hope to reduce the inequalities experienced at the end-of-life.

# Progress towards becoming an intelligence-led, Compassionate Sheffield

# 1. Background

In 2019 Sheffield's Health and Wellbeing Strategy was refreshed, with an overall aim of eliminating the gap in Healthy Life Expectancy across Sheffield. It took a life-course approach, with nine ambitions. The last of those ambitions was to ensure that 'everyone in Sheffield could live the end of their life with dignity and in a place of their choice'. This recognised that there is wide variation in experiences at the end-of-life in Sheffield – some are excellent, others, sadly, are not. Additionally, a paucity of high-quality intelligence in this area makes it hard for us to know who in Sheffield has a good experience or what, specifically constitutes a bad one.

A good end-of-life experience is said to be one where all physical, social, psychological and spiritual needs are met; it is known that good preparation improves that experience. A 'medical model' of death and dying would often view that preparation as something that happens between patients and professionals, which begins when the end of life is approaching.

A public health approach to death, dying and bereavement includes everyone affected by death and uses all of life's challenging experiences to prepare by: learning to use compassionate language and finding the confidence to offer, and to ask for help.

In practice, this approach allows communities and neighbourhoods to support individuals and families when they are at their most vulnerable. This has become known as a Compassionate Community approach.

In September of 2019 the Health and Wellbeing Board supported the development of a three-pillared approach to delivering the ninth ambition, namely:

- Developing Sheffield as a Compassionate City
- Taking an intelligence-led approach, and
- Transformation of clinical pathways.

The link to the full paper is given on the coversheet

## 2. Purpose of this paper

The purpose of this paper is to update the board with regard to progress of the Compassionate Sheffield project and the intelligence work, and to lay out some of the challenges and proposed next steps.

(NB: The 'Transformation of Clinical Pathways' element has made good progress and has been reporting to the HCP).

## 3. Compassion

Compassion can be misunderstood in two particularly unhelpful ways: it can be viewed as a version of 'kindness' and as such, too soft and fluffy to deliver transformational change, and/or as a natural, human reaction, common to us all: a free resource. It is neither.

Broken down into its component parts:

- Listening in order to learn, understand and empathise
- Taking *appropriate* action
  - it can be seen that compassionate approaches have the power to transform individual relationships, organisations, neighbourhoods and communities.

However, as with any significant change, resource is required to support and deliver it.

# 4. The Sheffield Compassionate City Project Partnership

Following a hiatus caused by the leaders of this work necessarily focussing directly on the pandemic response, the Sheffield Compassionate City Partnership came together in April 2021, initially to oversee recruitment and then to steer the work of the Programme Manager who began in post in August 2021.

At its outset it was constituted by partners who were contributing resource to the work, namely: Sheffield Clinical Commissioning Group (SCCG), St. Luke's Hospice, Sheffield Hallam University's Lab4Living and Sheffield City Council's (SCC) Public Health (PH) service. The work of the partnership has been supported financially by SCCG, St. Luke's Hospice and SCC PH.

The partnership now employs a programme manager and two community development workers (both started in post in August 2022 and work 4 days per week) – all employment contracts are hosted by St. Luke's.

## 5. Achievements to date

## 5.1. Compassionate City Project

## 5.1.1. Development of an identity

Compassion spreads in many ways, not least as a social movement, where people want to be part of something bigger than themselves. This is aided if there is a strong and simple sense of identity. A visual identity and some key messages for communications have been developed.



Barely a year old, 'Compassionate Sheffield' has gained both visibility and traction. This is evidenced by the fact that partners get approached about it in relation to a myriad of situations.

Compassionate Sheffield was founded within the context of death, dying, loss and bereavement. However, the principles can be applied to any context. Organisationally agnostic, it is a movement for Sheffield that has the value of 'compassion' at its core.

# 5.1.2. Advance Care Planning

Advanced Care Planning (ACP) helps people plan for the end of their life and is an important way of ensuring that services support the wishes of individuals. Primary care data highlights inequalities between different communities' engagement with ACP. This disparity drives inequity of experience for people in Sheffield.

Part of the reason for communities not engaging with ACP is a lack of information relevant to 'non-white British' people. Another crucial element is that primary care services do not have sufficient capacity to spend enough time to truly empathise and understand the relationship that these communities have with death.

Working with OPUS Independents and NHS Foundry Primary Care Network, Compassionate Sheffield are connecting targeted communities into the topic of 'Advance Care Planning'. By having conversations and facilitating workshops, we are supporting primary care services to work more effectively with Pakistani, Yemini and Roma communities.

The process will generate short videos, specific to each community that will provide tailored information on ACP. The videos will be made from the perspective of both people in the community and NHS services and will provide relevant information for communities and for primary care services.

# **5.1.3. Covid Memorial Project**

Compassionate Sheffield are co-ordinating the city's Covid Memorial activity in partnership with Sheffield City Council and others. To ensure the city's memorial activity is representative of the experiences of people and their communities three core elements have been designed.

 Stories from the Pandemic: Gathering stories from people across Sheffield and taking targeted action to capture the stories of people who were disproportionately affected during the pandemic. Stories are being gathered through online selfsubmissions, facilitated opportunities to populate postcards and video interviews.
 Over 300 individual stories have been collected so far.

All of the stories will be stored in the city's archives. A curated version of the stories will be exhibited in the millennium gallery in February 2023. A travelling 'community exhibit' and workshops will visit ten locations across the city. The narrative from all of the stories and experiences gathered from attendees at exhibitions will inform the city's central memorial garden.



# During the pandemic I lost...

### "

We lost our beloved dad and grandad, Leonard Gibson, who was the first person in Sheffield to officially lose his life to covid. He moved back to Sheffield from County Tyrone in his latter years, to be closer to family.

MICHELLE - WHARNCLIFFE SIDE, SHEFFIELD



### "

When I think about the pandemic, it's hard to separate out the pandemic from the murder of George Floyd. And certainly for our community, the African Caribbean community in Sheffield, the two were very, very interrelated. And what struck me was the same conversation my father had with me, as a young black boy needing to try harder needing to be better, not expecting what other citizens from the white majority community took as as a right. I was having that conversation with my grandson. And that shook me. It was shocking. And it made me think we still, yes, there's been improvements. I will be the first to say there have been improvements, but we've still got a long way to go.

DAVID - SACMHA, SHEFFIELD

- Community Grants: In August 2022, Compassionate Sheffield launched a community grants fund. The aim of this fund is to support community groups and organisations in Sheffield with grants of up to £2,000 to memorialise the Covid-19 pandemic. This will help to give people the time and space for reflection, acknowledging that the pandemic impacted everyone in different ways.

68 applications have been received from a diverse range of communities with a good geographical spread across the city. The grants have been assessed and a panel will meet on September 26<sup>th</sup> to confirm the outcome of these applications.

Approximately £80k will be awarded in community grants, with a further £20k held back to commission facilitated community memorial work with groups that did not engage with the grant application process.

The activity of these communities will be captured and recorded as part of Sheffield's story. Additionally, Compassionate Sheffield's Community Development Workers will meet successful groups and work with them to encourage the values of Compassionate Sheffield, aiming to increase confidence around the context of end of life, death, bereavement, and loss.

- Central Memorial: The site of Balm Green has been acquired for the development of a central Covid memorial. SCC have committed to erect a sculpture of a tree by Covid Remembrance Day next year (March 23<sup>rd</sup>, 2023). The stories gathered from around the city will be used to inform the design of the memorial garden. Plans are under development that could see school children invited to design leaves for the tree on which some of Sheffield's messages from the pandemic could be inscribed.

## 5.1.4. Death is a Part of Life: Let's talk about it....

As part of Sheffield's Festival of Debate, Compassionate Sheffield partnered with Sheffield Hallam University's Lab4Living programme and hosted a programme of events that encouraged members of the public to come and talk about death.

The workshops were facilitated by activated citizens and used a creative structure combining the approach of Life Cafes (developed by Lab4Living, in partnership with Marie Curie) and Death Cafes (worldwide volunteer movement). The events were fully booked and 34 people attended the sessions, with 100% of people who evaluated the sessions saying they would come to a similar event again in the future.

One of Compassionate Sheffield's Community Development Workers is a trained End of Life Doula. They are working with members of the community to create safe space for people to talk about death. The aim is to provide sufficient confidence for attendees to facilitate their own conversations or workshops that encourage people to talk with confidence about death.

## **5.1.5.** Compassionate Companions

At some point, everyone will interact with the end of life; knowing how to navigate this important part of life can be challenging. Equally staff, volunteers and members of communities supporting people approaching the end of their life, often don't know how to help.

Partnering with St Luke's Hospice, SCCCC, FaithStar and End of Life Doula UK, workshops are being delivered to staff and volunteers to help enhance their work in current roles. The workshops are focused on improving confidence to provide practical and person-centred support to people as they approach the end of their life.

Staff and volunteers naturally interact with people who are dying as part of their role, adding confidence to their compassion, and equipping them with extra, relevant knowledge will help them provide non-clinical support to the person who is dying. Topics of the three-day training being piloted in October 2022 include: will writing, grief, the dying process, navigating the care system, funeral planning, family dynamics and power of attorney.

After piloting the training, the ambition is to make information and learning available to anyone who wants to learn more, including members of the public from Spring 2023. The model has been adapted from a similar approach taken in Suffolk, with the project's partners we are working to ensure the offer matches the needs of people in Sheffield.

# 5.1.6. Death rituals and symbols: Community arts project

During the pandemic, people of Sheffield were distanced from the rituals and ceremonies that support the processing of death. Each community and individual has their own, unique relationship with death. These relationships are often played out through rituals and symbols.

Partnering with Ignite Imaginations, five different communities from across Sheffield are creating pieces of art. The artists facilitating this work will be a part of the community they are working with. The work will celebrate the different approaches to death, whilst using the topic of death to generate a sense of commonality.

After creating these individual pieces, the different groups will come together to showcase their work at the Millennium Gallery in early 2023. With the ambition of using the highly emotive and universal topic of death to connect across communities, differences can be explored, leading to a better understanding of inequity of experience across the city.

# 5.1.7. Warm Spaces and Welcoming Places

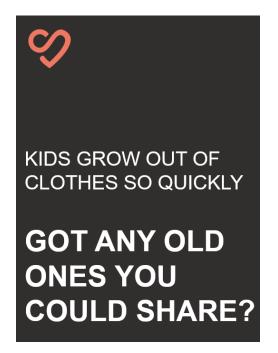
The values of compassion and the work of Compassionate Sheffield is not limited to the topic of death, dying, loss and bereavement. Over the winter of 2022/23 inequalities within the city will be further exposed and we are working to support the Warm Spaces and Welcome Places initiative.

Compassionate Sheffield's Community Development Workers will be present in community spaces and will deliver activities that aim to be fun and engaging and that bring people together. We plan to host movie showings, facilitate workshops, compassionate

conversations and other creative activities that encourage and inspire compassion within communities.

As well as delivering creative sessions, action-based messaging is being developed to inspire and encourage people to club together. Sheffield's communities are strong and its people, compassionate. Compassionate Sheffield aims to be an active partner and supports the city's Cost of Living Crisis Tactical Group.





# 5.2. End of Life Intelligence Workstream

## 5.2.1. Comprehensive record of service activity

Following the Health and Wellbeing Board support for the development of an integrated intelligence function, a partnership was brought together including representatives from commissioning and end-of-life care provider services, Public Health, both Sheffield Universities and national expert bodies to develop the Sheffield End-of-Life Intelligence Delivery and Advisory group with additional support coming from Compassionate Cities UK and Public Health England.

As with the Sheffield Compassionate City Project, the pandemic drew many partners away and progress was slower than had been hoped. That said, the group has assembled a large, quantitative dataset of deaths in hospital and the community and has successfully tested and applied locally-driven analytics, providing a more detailed exploration than national initiatives collating and publishing data on end-of-life care are currently able to provide.

This has realised the first stage in a longer-term ambition to undertake (local and Integrated Care Board) health needs assessments to better understand current, and predict future, end-of-life health and care needs.

# 6. Challenges

## 6.1. Compassionate City Project

# 6.1.1. Insecure funding

Compassionate Sheffield is a programme which in spite of being in its infancy is demonstrating that community-focussed, asset-based approaches are a feasible way of improving preparation for, and experience around the end-of-life. We know that such 'left-shift' is likely to offer sustainable, improved outcomes in the long term. Those outcomes are almost impossible to measure in the short-term, which has always been a challenge to commissioners.

However, such interventions are likely to be as cost-effective (if not more so) than traditional, medical interventions and may, indeed be cost-saving if taking a system-wide, long-term perspective.

These approaches do not come for free. To date, the partnership has received £463k (£207k excluding the Covid Memorial funding) in financial support – in the form of nine, discreet, ad hoc 'packages'.

This approach to funding does not give the programme the security and ability to plan even for the medium-term future, which is necessary to maximise its impact. It also takes staff time away from developing the programme, to make the case for packages of one-off funding – recurrently.

## 6.1.2. Limited capacity

The 'listen in order to learn, understand and empathise, then take appropriate action' interpretation of compassion can be shown to have a positive impact way beyond end-of-life situations.

Members of the Compassionate Sheffield partnership have been invited into conversations and asked to share methodologies with a broad range of events and settings: e.g. schools, dementia charities, reducing inequalities in primary care, homelessness, age-friendly city, SEND, HealthWatch, care home commissioning and transformation of large, public-sector organisations.

The potential to broaden the programme's scope and reach is limited by the small size of the team.

## 6.2. End of Life Intelligence Workstream

## 6.2.1. Ongoing resource

Whilst impressive to even national-level partners, the baseline dataset does not in itself help us to reduce inequalities at the end-of-life. Quantitative data alone cannot provide answers to essential questions beyond monitoring proxies of good end-of-life experiences

e.g. dying at home. If the system is to be transformed to ensure all have a good end-of-life experience, many other questions need to be answered. For example:

- How many people in Sheffield have a good death?
- Who gets a good death and is that fair?
- Could death be better if services were structured differently or if society viewed it differently?
- Can we make dying more cost-effective?
- What happens to those left behind after death?

Recent research has established that none of the current nationally available end-of-life care metric categories are able to compare the quality of end-of-life experiences for all people in all settings. In practical terms that means that if we in Sheffield want to answer those questions, we will have to do it ourselves. It is known that the only accurate way to understand if end-of-life experiences are good or bad is to combine qualitative with quantitative data.

By exploring and understanding inequalities in community and individual experience, service use, and needs, the Compassionate Sheffield programme can provide just such qualitative data in the form of stories, insights and community-based learning.

This can all, in turn be combined with socio-demographic, census and other public health data to examine trends, patterns and inequalities. This analysis will allow for a richer understanding of the end-of-life in Sheffield as experienced by individuals, neighbourhoods and communities. Only by understanding the differences between what people value at the end of life and the experiences they and the people around them have, can recommendations for action be developed, with potential to better support existing community assets and to replicate benefits of compassionate cities seen elsewhere in the UK and globally.

The potential for a truly intelligence-led approach is in reach, but does need analytical support to get there.

# 3.0 WHAT NEEDS TO HAPPEN TO MAKE A DIFFERENCE IN THIS AREA?

To maximise the impact of both the Compassionate City and Intelligence elements of this work – a sustainable approach to funding needs to be secured.

## 4.0 QUESTIONS FOR THE BOARD

- We ask the board to note the work that has been done in a relatively short period and challenging circumstances. Does the board agree that this work is an important foundation to achieve the ninth ambition of the H&WBS and as such, does it sponsor its continuation?
- Will the board agree to receive further updates in due course after a period of sustainable funding?

• Can board members refresh individual organisational commitment to the integrated intelligence approach?

# **5.0 RECOMMENDATIONS**

• We recommend that the H&WB board asks the Sheffield Joint Commissioning Committee if they will take this work forward as part of Sheffield's programme of integrated commissioning.