

'What matters to you?' day

Annual Report 2019





people



Building positive relationships



Having more meaningful conversations



Supporting shared decision making



Personalising approaches to care

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Foreword

One of the things the 'What matters to you?' movement is helping us to realise is that, despite all the incredible advances we have made in modern healthcare, there is no substitute or technical fix for a sincere compassionate human connection between people providing healthcare and people receiving care or support. In the busyness of the modern healthcare system with its industrialised processes, electronic records and high-tech treatments and medicines, it is easy to overlook the fundamental importance and effect of compassionate human connection.

There is art and science required in delivering healthcare and the ability to make a compassionate connection lies at the core of the art of healthcare provision. In our busy organisations healthcare professionals and patients can be like ships that pass in the night, a brief interaction in a blur of activity – this is not good for anyone, least of all patients and their families.

Even a brief conversation about the things that really matter, or just a word and a look to let someone know you care, is a line thrown between ships that draws them together and provides an opportunity to connect in ways that are meaningful and powerful. We often have a wealth of information about *patients like this*, but until we *draw up alongside* and connect with the person in front of us we cannot know how to support or care for *this patient*. Evidence increasingly shows that failure to connect in this way not only has a detrimental impact on the emotional well-being of patients and healthcare professionals, it also impacts negatively on the effectiveness and safety of the care and treatment provided. When there is compassionate connection wounds heal more quickly, pain is reduced and anxiety is eased. For healthcare workers, pride in work, job satisfaction and well-being increase, and emotional burnout decreases.

With these things in mind we realise that the 'What matters to you?' movement and 'What



matters to you?' conversations are not an optional extra or about a single day of the year. They need to be at the heart of every interaction, every day and with every person, every time. We hope you will join us by making carefully guarded space in your daily interactions with colleagues and patients alike, for conversations about the things that really matter.

Shaun Maher (right) in conversation with Tommy Whitelaw, Project Lead at the Alliance, about the power of 'What matters to you?' conversations and the spread of the movement.

Shaun Maher, Strategic Advisor for Person-Centred Care, Healthcare Quality and Improvement Directorate, Scottish Government

Introduction

'What matters to you?' day aims to encourage and celebrate more meaningful conversations between people who provide health and social care and the people who receive care and support, as well as their families and carers.

This initiative encourages professionals to move their conversation focus from "What's the matter with you?" to "What matters to you?" This helps to support the development of high quality compassionate support, care or treatment focused around what people really need and want.

Scotland has co-ordinated and hosted the annual 'What matters to you?' day since 2016. Many of the countries that engaged with Scotland over this time have gone on to co-ordinate their own local campaigns, embedding this campaign at an international level.

The value of the 'What matters to you?' approach has been widely adopted and recognised in Scotland. The Chief Medical Officer, Catherine Calderwood, in her annual report 'Realising Realistic Medicine' published in February 2017, proposed that 'What matters to you?' conversations are the foundation of high quality shared decision making approaches. In her annual report published in April 2018, 'Practising Realistic Medicine', the Chief Medical Officer re-emphasised this important question, saying: "Through shared decision making we must get better at determining what matters most to patients. Practising Realistic Medicine requires care that is coproduced in partnership with the people receiving it – person-centred, holistic care. We need to readdress the balance."

In his final NHS Scotland Chief Executive's Report ³ published in December 2018, Paul Gray said: "Creating the conditions for person-centred care also involves paying attention to the question, 'Who Matters To You?'. There is a growing recognition across the NHS of how important it is to develop a family-friendly culture that encourages and supports people to remain connected with family and loved ones while they are in hospital. The Scottish Government is supporting this growing movement in the NHS with a commitment in the Programme for Government 2018/19 to have flexible visiting in place across NHS Scotland by 2020, so that anyone can be with the important people in their lives while in hospital."

¹ Realising Realistic Medicine: Chief Medical Officer for Scotland annual report 2015-2016: https://www.gov.scot/binaries/content/documents/govscot/publications/progress-report/2017/02/chief-medical-officer-scotland-annual-report-2015-16-realising-realistic-9781786526731/documents/00514513-pdf/govscot%3Adocument

² Practising Realistic Medicine: Chief Medical Officer for Scotland annual report, 2016-17: https://www.gov.scot/binaries/content/documents/govscot/publications/progress-report/2018/04/practising-realistic-medicine/documents/00534374-pdf/00534374-pdf/govscot%3Adocument

³ NHS Scotland Chief Executive's Report 2017-2018: https://www.nhsscotannualreport.scot/

This focus on helping people to stay connected to their loved ones in hospital has flowed from our focus on 'What matters to you?' conversations in Scotland. Moving away from set times controlled by the healthcare system to a compassionate focus on each person and the people that matter most to them.

The 'What matters to you?' team in Scotland is connecting more and more with our colleagues across the globe. At this point these connections are mainly taking place in health and social care settings but as we are finding here in Scotland the value of the 'What matters to you?' approach is beginning to be recognised in different sectors, for example in education.

We are also seeing a growing recognition of the importance of supporting a compassionate culture. Staff can't be expected to focus on 'What matters to you?' conversations when their working conditions are not orientated in the same direction. As American engineer W. Edwards Deming said: "A bad system will beat a good person every time"⁴.

The Institute of Healthcare Improvement's Joy in Work framework⁵ introduces the 'What matters to you?' approach as a way to '...engage in a participative process where leaders ask colleagues at all levels of the organisation, 'What matters to you?' — enabling them to better understand the barriers to joy in work, and co-create meaningful, high-leverage strategies to address these issues...' It is encouraging that it is being adopted by the health and social care workforce, where managers and teams are using the 'What matters to you?' conversation as a core component of supporting wellbeing in the workplace.

http://www.ihi.org/resources/Pages/IHIWhitePapers/Framework-Improving-Joy-in-Work.aspx

⁴ Quote by W. Edwards Deming at a February 1993 Deming Four Day seminar in Phoenix, Arizona

⁵ IHI Framework for Improving Joy in Work, 2017:

What we did

Working group

The 'What matters to you?' day working group has led co-ordination and promotion of this initiative in Scotland since 2016. This group includes members of the public, representatives from Healthcare Improvement Scotland, Scottish Government, NHS boards, and representation from third sector organisations including the Health and Social Care Alliance Scotland (the ALLIANCE), CEMVO Scotland and See Me Scotland (see Appendix 1).

Based on feedback from previous years, members of the Scottish 'What matters to you?' working group began thinking about how to look at the impact asking 'What matters to you?' has had on services and how providers had used feedback to change the way they work.

An evaluation report, "What matters to you?": supporting more meaningful conversations in day-to-day practice', was commissioned by the Evidence and Evaluation for Improvement Team (EEvIT) at Healthcare Improvement Scotland. This was a multiple case study evaluation, carried out with people or groups who had participated more than once in the initiative to help determine:

- how have particular healthcare organisations applied 'What matters to you?' in their day-to-day practice?, and
- what lessons can be learned about the enablers and barriers to using 'What matters to you?' in practice and the specific actions that have helped overcome barriers?

The report suggests that it is important for organisations and individual practitioners to have the flexibility to develop their use of 'What matters to you?' and to be able to structure conversations in ways that are meaningful for the people receiving care in their particular context and that this aligns with existing person-centred care.

It also found that there needed to be careful thought about where and how people are engaged in conversations to ensure that everyone's needs and experiences are being considered, as one size will not fit all. For example, people who may be more likely to experience barriers to communication need to have an equal opportunity to engage in 'What matters to you?' conversations and articulate what matters to them.

Resources

This year the working group used the same physical resources that were used in 2018 to enable individuals and teams to take part in 'What matters to you?' day.

⁶https://ihub.scot/improvement-programmes/evidence-and-evaluation-for-improvement/summaries-of-evaluation-work/multiple-case-study-evaluation-of-what-matters-to-you-in-day-to-day-practice/https://www.whatmatterstoyou.scot/wp-content/uploads/2019/09/wmty-evaluation-report-May2019.pdf

The online resources were expanded for 2019 and this is ongoing work based on feedback and comments received. One example of this is that during 2019, we were very fortunate that people participating from various countries who adapted our editable resources shared them with us, expanding the available languages of resources that will be available to all in 2020.

As in previous years, resource packs were distributed across Scotland, at no cost to the recipients. Resources included badges, pens, posters, post-its and stickers (see Appendix 2 for a full list of resources and costs). These resources were also available online for download and were used and adapted by people participating both in Scotland and across a range of other countries.

Some additional resources were provided as online materials only. These included a guidance document, feedback postcard, pull-up banner template and public information leaflets. Making these resources downloadable allowed people to adapt them for their local areas or settings.

To support people from as many backgrounds as possible to learn more about the day and to participate, public information leaflets were developed and translated into the four most commonly used languages across Scotland: Arabic, Chinese, Urdu and Polish. We also produced a short film clip using British Sign Language. We will be expanding this range for 2020. All of these resources are available to view and download online.⁷

Communication

To support participation in 'What matters to you?' day 2019, we used a range of communication methods to let people know about the day and how they could get involved. These methods included the following.

Email

Direct email communication with a wide range of health, social care and third sector networks across Scotland, including:

- health and social care partnership chief officers
- NHS board chief executives
- NHS board executive nurse directors
- public involvement and engagement leads
- local authorities, and
- third sector organisations.

All participants who registered to take part in 2018 were also contacted directly by email to give them early notification of 'What matters to you?' day 2019 along with information about how to get involved again.

⁷ 'What matters to you?' day online resources: www.whatmatterstoyou.scot

Social media

Based on the level of activity on Twitter during the previous campaigns, there was a continued focus on promoting 'What matters to you?' day 2019 using this method. We used the hashtag #WMTY19 to promote and share 'What matters to you?' day, along with the dedicated Twitter account @WMTYScot.

We also used the 'What matters to you?' day Facebook account, www.facebook.com/whatmatters2you, to reach a wider public audience, as this has been shown to be effective in previous campaigns.

Website

The 'What matters to you?' website, <u>www.whatmatterstoyou.scot</u>, supported those taking part in a range of ways and featured:

- blogs from colleagues across health and social care about why the 'What matters to you?' approach was important and how they were planning to take part
- examples of what people did in previous years
- downloadable campaign resources, and
- a contact form to allow people to register and request resources.

'What matters to you?' - International Group

Following 'What matters to you?' day in 2019 and in order to share experiences, offer support and discuss new ideas, a monthly video call was set up with national and international partners taking part. This is a fairly new initiative but it has proved to be a popular way of communicating around the globe.

Some early work has included looking at developing subgroups with specific tasks including one with a remit to develop an international sharing repository of 'What matters to you?' toolkits, examples of best practice, videos, implementation guidance and resources. One subgroup already in place is the Writing Group which is currently scoping which journals to target for publication of 'What matters to you?' articles in 2020.

Participation

Between 1 March and 30 July 2019, a total of 627 individuals and teams from across Scotland registered to take part in 'What matters to you?' day 2019 activities. This is a small increase from 612 in 2018.

Two possible factors that may account for the small increase in registrations are:

- evidence of wider unregistered involvement, which has been gathered through
 Twitter, Facebook and conversations with care teams around the country, and
- as the initiative matures, teams and organisations have taken ownership and don't feel they have to formally register with the national campaign.

'What matters to you?' 2019 Participation in Scotland

During 2019, a wide range of organisations participated across Scotland. The types of organisations participating can be seen in Figure 2 below.

Figure 2: 2019 Distribution of Scottish registrations by organisation type

Care home	37	NHS Board Special	30
Early years	2	NHS Board Territorial	408
Education	2	Other/Individuals	19
HSCP	41	Primary Care	17
Local Authority	25	Third Sector	35

'What matters to you?' 2019 International Participation/Registration through 'What matters to you?' Scotland

Nine new countries joined the initiative for the first time this year: Argentina, Egypt, Estonia, Germany, Indonesia, Kenya, Pakistan, Peru and Portugal. This increased the total number of countries who have participated in 'What matters to you?' day since 2016 to 42. These countries can be seen on the map in Figure 2 and the numbers of registrations from each country in 2019 is listed in Figure 3.

Whilst Belgium, Brazil, Canada and Denmark now co-ordinate their own national activities, the number of teams registering with us from outside Scotland has continued to be a rising trend this year.

Figure 3: Participating countries 2019



Figure 4: Number of registrations from participating countries

Country	Number of registrations	Country	Number of registrations
	registrations		registrations
Argentina (AR)	1	Luxembourg (L)	1
Australia (AU)	7	Northern Ireland (NI)	13
Brazil (BR)	11	Pakistan (PA)	1
Canada (C)	5	Peru (PE)	1
Egypt (EG)	1	Portugal (PO)	1
England (EN)	285	Scotland (SC)	628
Estonia (ES)	2	South Africa (SA)	2
Germany (G)	1	Sweden (SW)	3
Indonesia (IN)	1	USA (US)	24
Ireland (IR)	4	Wales (W)	1
Kenya (K)	1		

Participation through social media

Twitter

Through Twitter we continue to track significant international activity across the world, with people sharing photos, activities, successes and feedback using @WMTYScot and #WMTY19. This year we observed a variety of different hashtags being used and for 2020 we are exploring ways to include these in our statistics.

For #WMTY19 we invited our international participants to take part in a "Mexican Wave" of Twitter activity by posting a brief message when it was 9am in their country. We saw tweets from countries across the globe supporting this initiative, including Afghanistan, Algeria, Australia, Brazil, Canada, India, Mexico, New Zealand, Nigeria, Pakistan, Peru, South Africa, Thailand, USA and most of Europe. We will further publicise this activity in 2020 to help promote the sense of belonging to something that is truly global.

Between 13 April and 10 June 2019 there were well over 33 million impressions made on Twitter using #WMTY19. This is a huge increase on the previous year when, in a four-month period between 1 March and 30 June 2018, over 25 million impressions were made. The Twitter statistics for the days surrounding 'What matters to you?' day 2019, which are slightly lower than last year, can be seen in Figure 5 below.

Figure 5: #WMTY19 Twitter activity between 5 and 7 June 2019

Twitter 2019 Figures

21.082 million impressions

7,898 tweets

2,487 participants

110 average tweets per hour

3 average tweets per participant

Facebook

Between 1 January 2019 and 31 July 2019 the Facebook page (www.facebook.com/whatmatters2you) attracted an additional 189 followers bringing the total number to 722, increasing its visibility and gaining:

- 691 likes
- 1,189 views
- a reach of 17,631, and
- 4,655 engagement with posts.

Website

The website (www.whatmatterstoyou.scot) draws interest throughout the year with peaks both before and after 6 June. Between 1 March and 30 June 2019, the website showed an increase in activity from the 2018 figures and received 42,986 views by 14,462 people. The 'What matters to you?' documents were downloaded on 6,275 occasions during the same timescale.

Feedback

In August 2019 all 627 registered teams or individuals were asked about their experience of taking part in 'What matters to you?' 2019 via an online survey. We received 145 fully completed and a further 113 partially completed responses. In identifying the sectors respondents worked in, 50% said they worked in the NHS and a further 23% said they worked in health and social care or other healthcare organisation. People participating in Scotland comprised 61% of the total respondents, and 31% were in England. Most participants, when asked what they did on the day, spoke about having conversations with patients, clients or other staff members, although some also mentioned taking the opportunity to introduce a survey or questionnaire.

Additionally we encouraged participants to share their feedback about their 'What matters to you?' day activities using:

- email
- an online feedback form, or
- Twitter.

Feedback included information about activities that participants arranged and took part in as well as the impact of 'What matters to you?' conversations.

The amendments made to the feedback methods in 2018 and continuing into 2019/2020 are intended to support participants to more effectively describe the impact of the conversations rather than simply the activities that were organised.

Outcomes and impact

This section presents a small selection of case studies illustrating the different ways people took part and the outcomes and impacts of 'What matters to you?' day 2019. More case studies can be found on our website at: www.whatmatterstoyou.scot/wmty-day-2019/

Case Studies

Below is a sample summary of case studies that have been shared with us.

NHS Fife

A patient who had very complex needs and was unable to leave his single room had been on the ward for 5 months. His only social contact was with his wife, who visited every day, and the nursing staff looking after him. His mood was very low and staff were concerned that he might not leave hospital and that he was losing his fight.

During a conversation with a member of staff, the patient mentioned that he had two dogs but he didn't think they would remember him as he had been in hospital so long. His eyes filled with tears as he spoke about them. The staff member made enquiries with the infection control team to ask about the possibility of allowing animals into the ward and was advised that, as long as a risk assessment was carried out, the dogs could be allowed to come in.

The patient's wife was asked if she would like to bring the dogs in as a surprise for her husband and she was delighted to help and arranged for them to be brought in the next day. It was hard keeping such a big secret from the patient but worth it as he was overjoyed to see his beloved pets, his mood lifted and he began to aim for home. He remained in hospital for another 6 weeks, and during this time his wife was able to bring the dogs in one day every weekend when there were fewer people around.

This simple gesture appeared to help change his outlook and build relationships between staff and his wife. Since discharge, the patient has had to return to hospital several times since, for a few days at a time, and always requests to come back to the same ward as he feels secure and well cared for there. That is a real compliment to the staff.

As a result of this experience NHS Fife has updated its guidance on the management of pets and animals in hospital.

East Lothian - Support from the Start

In East Lothian, Support from the Start⁸ family workers are encouraged to use the 'What matters to you?' model for conversations with clients to enhance the engagement process. The workers help parents identify the goals they have for themselves and only then

⁸ https://www.eastlothian.gov.uk/downloads/download/12762/support from the start

develop plans of support. The following is one woman's description of what mattered to her in the relationship with a family worker.

What do you think was important about your contact with the Family Support Worker?

"It has been important to me as it has built up my confidence. Having someone neutral to talk to so it wasn't always putting it on friends and family. It is nice to have someone experienced. It is good to have a mutual sounding board."

What did you hope for from a relationship with the Family Support Worker?

"I wasn't sure to start with, I knew people needed your support more than we did but when support was offered to me I gladly took it. I am really happy with the support I get and I really value it and look forward to you coming. I feel you have got to know me and my values really well. You have built my confidence and have been a good emotional support but also a great practical support by allowing me to go running, which means a lot."

What mattered to you in your relationship with the Family Support Worker?

"Trust definitely matters. It has been important that you are like-minded and seem to understand me as a parent. You listen really well. I like the Mind Mindedness work we are doing as that is the type of parenting I want to practise. I can tell that you have adapted your techniques and advice to suit me as what would suit me might not suit another parent I work with."

Key learning and next steps

Following each 'What matters to you' day, it is important to consider how to maximise the impact in the following year so that more people can benefit thinking about and acting on this important question. We have identified the following as key learning and development issues from 'What matters to you?' day 2019.

Participation and reach

The number of registrations for 2019 showed a small increase from 2018 and shows a pattern of team registration rather than individual registrations. The majority of registrations are from healthcare providers, with an increasing number from health and social care partnerships this year.

The international appeal of 'What matters to you?' day continued, with nine new countries registering to participate in 2019. Various other countries also co-ordinated the day within their own nations and continued to link in with the Scottish team, although only registrations directly made via the website are included in this report.

For 'What matters to you?' 2020 we will continue to build engagement and involvement across all sectors. We have received anecdotal feedback that the 'What matters to you?' approach has been used in nurseries, schools and colleges and also in at least one Job Centre.

Demonstrating impact

The learning taken from the impact feedback following 'What matters to you?' in previous years was used to adapt the feedback methods for 2019 and this is an ongoing piece of work. The informal feedback we have received indicates that there have been more impacts recorded, changes made in 'support practice' and actions taken following 'What matters to you?' conversations. We are still encouraging participants to share their outcomes with us so that we can share and support other similar work.

For 2020 the focus will be on what happens *after* 'What matters to you?' day. What did participants do after the conversations were held? Did providers continue to ask the question? Did they find anything they could change to improve? Did they make any changes? To facilitate the recording of the next steps we have piloted a brief form⁹ for people to complete. The shorter form could lead us into conversation with participants and encourage and assist them to provide fuller information and perhaps a fuller case study for sharing.

⁹https://www.whatmatterstoyou.scot/wp-content/uploads/2019/11/20191122-WMTY-impact-0.4.pptx

Conclusion

Participation in 'What matters to you?' day 2019 increased in all of the different areas we are currently able to measure and in some areas it increased considerably.

For the team, the challenge continues to be to turn all of the anecdotal evidence we see and hear on the embedding of the principle, into hard evidence of the difference it is making in the daily lives of patients, carers and staff.

When we asked people who registered for 'What matters to you?' in 2019 what they learned from asking the question "What matters to you?" the most common answers were that, generally, it wasn't major, health-related things that mattered most to people but relationships, dignity and respect and communication. When it was a practical issue that mattered it was often an 'easy fix'. People also said that they were often surprised by the answer, which seems like a good indication to keep asking "What matters to you?" and not to make assumptions.

Appendix 1: 'What matters to you?' day 2019 working group members

Group member	Role
Safia Ali/	Race Equality Mainstreaming Officer
Parveen Khan	CEMVO Scotland
Margaret Anderson	Public Partner Healthcare Improvement Scotland
Claire Curtis	Associate Improvement Advisor, Person-centred Health and Care
	Healthcare Improvement Scotland
Diane Graham	Improvement Advisor, Person-centred Health and Care
	Healthcare Improvement Scotland
Shaun Maher - Chair	Strategic Advisor for Person-Centred Care, Healthcare Quality and Improvement Directorate, The Scottish Government
Rob MacPhail	Communications Officer
	Healthcare Improvement Scotland
Margaret McDonald	Public Partner Healthcare Improvement Scotland
Louise McFarlane	Performance Analyst, Scottish Health Council
Susan McLaren	Administrator, Scottish Health Council
Gavin Paterson	Partnership Engagement Officer
	North Ayrshire Health and Social Care Partnership
Jennifer Rodgers	Chief Nurse, Paediatrics and Neonates
	NHS Greater Glasgow and Clyde
Susan Siegel	Public Partner Healthcare Improvement Scotland
Tommy Whitelaw	Project Engagement Lead
	Health and Social Care Alliance Scotland

Appendix 2: 'What matters to you?' day 2019 costs

Item	Cost (including VAT)
Resources	
Badges	£4,145.00
Posters	£334.00
Stickers	£614.80
Design	In-house
Notebooks	£1,511.40
Lanyards	£2422.50
Post-its	£419.25
Pens	£229.00
Carriage	£145.00
	<u> </u>
Postage	
Badges, posters and stickers	£1,784.51
Envelopes	£101.52
Overall total cost	£11,706.98

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