

‘What matters to you?’ day

Annual Report 2020



Achieving better
outcomes for
people



Building
positive
relationships



Having more
meaningful
conversations



Supporting
shared
decision making



Personalising
approaches
to care

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2 Foreword



2020 has been a year like no other and all of us have experienced dramatic changes in our lives in one way or another. Some have lost people close to them, others have been separated from loved ones and others have had to postpone or adapt important events in their lives. Things have been especially challenging for those people receiving care or support in health and social care settings and for the staff working in these care teams. We are incredibly grateful for the sacrifices people have made and the dedication and compassion of our health and social care staff.

All of us have been affected in one way or another and had to get used to new ways of interacting because of the challenges presented by COVID-19 and these experiences have reminded us just how important human connection is to our emotional and physical well-being. It is for this reason that our focus on “What matters to you?” in 2020 was more important than ever. Your efforts to listen and connect meaningfully with people made a big difference and the stories of people going the extra mile to deliver great care and support are inspiring.

Not being able to reach out and touch someone in distress or hug someone you love is something we have missed greatly over the past twelve months, but at the same time this has served as an important reminder of the value of human connection. A good conversation about the things that really matter can help us to share experiences and discover ways to cope with the challenges we face. We have had to learn to do this in new ways, over virtual platforms online or socially distanced, but we have still been able to do it and that has been a tremendous source of support and encouragement.

I’m sure, like me, you are looking forward to the next normal. A world where we don’t have to worry about hugging our loved ones or breathing out around colleagues and those for whom we care. Until that day, which is coming, I promise, I am grateful for your continued focus on “what matters to you” and the difference this makes every day to people’s lives and experiences of care and support – please keep it up! We look forward to a brighter future and a continued focus on providing high quality, compassionate care and support for the people of Scotland.

Professor Jason Leitch

National Clinical Director of the Scottish Government

3 Introduction and Context for 2020

‘What matters to you?’

The ‘What matters to you?’ 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 such as the Health and Social Care Alliance Scotland (the ALLIANCE), CEMVO Scotland and See Me Scotland (see Appendix 1).

‘What matters to you?’ (WMTY) day, around 6 June each year, aims to showcase, encourage and celebrate more meaningful conversations so that they take place routinely between people who provide health and social care and the people who receive care and support, as well as their families and carers. In short it’s so that these conversations are embedded as just how we do things.

Against the background of the worldwide coronavirus pandemic in 2020, the ethos of ‘WMTY’ has never been more important in what has been a challenging year for everyone but in particular for those working in and those receiving health and social care.

Co-ordinating WMTY day in 2020 as we had done in previous years was not going to be possible due to the many pressures on those working in the health and care system, which included setting up and running the Louisa Jordan Hospital, working in other frontline healthcare positions or moving to home working with no access to their workplace.

In the March 2020 planning meeting, the decision was taken to suspend registration for this year due to the pandemic and the restrictions in place at that time. Many factors were taken into account in reaching this decision, including the health and safety of staff, patients and carers; and Scottish Government guidelines. Other crucial but unknown factors in the decision included the path the virus would take, how long it would be a danger and the mitigations needed to prevent the spread.

We had early indications that 2020 was shaping up to be an exceptionally busy year for WMTY day. Enquiries were coming in much earlier than usual. Allowing people to freely download and adapt resources encouraged participation, including overseas and in non-English speaking countries. With all the challenges for this year, 31 countries still took part, ranging from Australia to Guinea and Kuwait to Haiti and many more.

Since the beginning in 2016, WMTY hasn’t relied on traditional, formal communication channels to connect with organisations. There is a strong focus on social media with Twitter being the most successful channel. Even with no registration of participants taking place, the level of Twitter activity using #WMTY20 around the 9 June surprised us by being only slightly lower than in previous years.

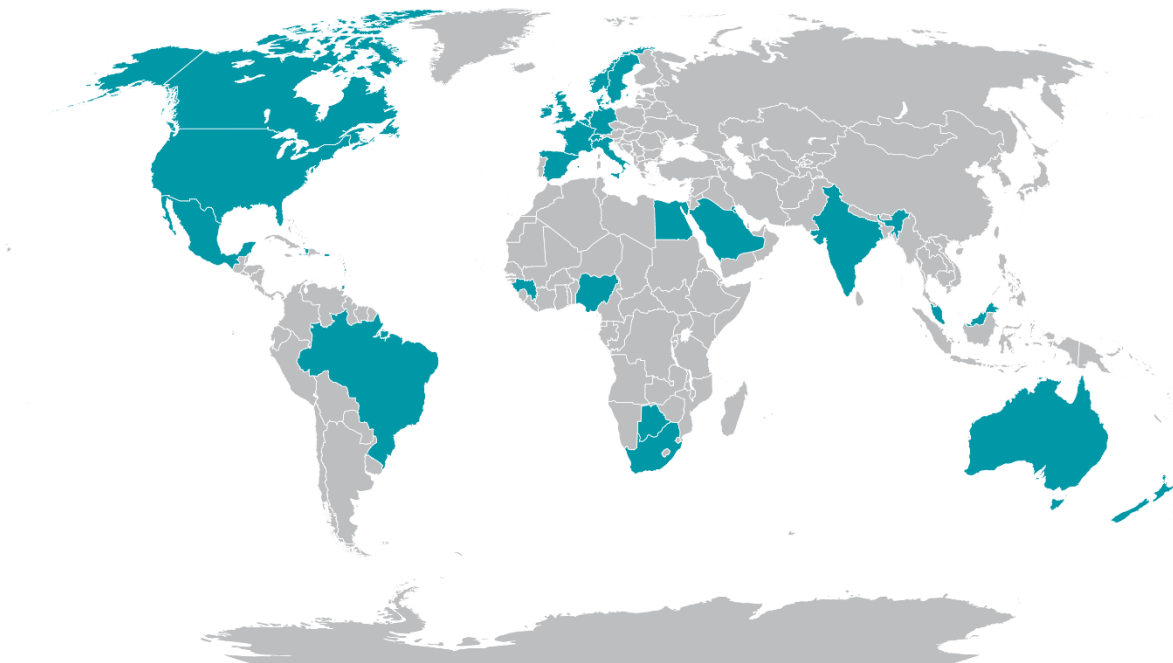
Of course, the purpose of the 'What matters to you?' movement is not about the campaign resources or counting countries participating, although that does help to show the growth and reach of the movement. WMTY is about conversations, human connections and understanding what people really want and need to live the best life they can. In health and social care when people are routinely asked 'What matters to you?' it leads to more positive experiences, results in higher quality and better outcomes and working in an environment with a 'What matters to you?' culture has a positive impact on staff experience.

As we have adjusted to a different way of working during the pandemic in 2020 and begin our planning for WMTY21, we anticipate that we will continue to work differently in 2021. To facilitate this, we have begun a re-design of the website to make access to download online resources easier and more streamlined. It is our intention this year to invite people to register so that we can keep them updated on WMTY activities and news.

4 Statistics

This year #WMTY20 Twitter activity was noted in 31 countries. These were:

Australia	France	Malaysia	St Lucia
Belgium	Germany	Malta	Saudi Arabia
Botswana	Guinea	Mexico	Scotland
Brazil	Haiti	Netherlands	Sweden
Canada	India	New Zealand	Switzerland
Denmark	Ireland	Nigeria	Trinidad & Tobago
Egypt	Italy	N. Ireland	United States
England	Kuwait	Norway	Wales



Twitter #WMTY20 Figures between 1 – 17 June 2020

- 19.534 million impressions
- 5,676 tweets
- 1,816 participants
- 3 average tweets per participant

Website

The website (www.whatmatterstoyou.scot) draws interest throughout the year with peaks both before and after June. Visits to the website between 1 March and 30 June 2020 showed a significant decrease in activity compared to the previous year – although it should be noted that this time period corresponded to the national COVID-19 lockdown and promotional activity was deliberately reduced in order to allow frontline staff to concentrate on responding to the pandemic. During this 4-month period, the website received 18,607 views.

Facebook

Between 1 January 2019 and 31 July 2020 the Facebook page (www.facebook.com/whatmatters2you) attracted an additional 112 followers bringing the total number to 834. Due to changes to Facebook it has not been possible to extract other comparative figures for 2020.

5 Case Study Summaries

Full text for all case studies available on www.whatmatterstoyou.scot

Gypsy Traveller Community Engagement

Sometimes asking ‘What matters to you?’ can have a really quick answer and sometimes if it’s something you can fix, a really quick resolution. This case study shared by Gillian Ventura from the Community Engagement Directorate in Healthcare Improvement Scotland has a much longer timescale. The improvement that was needed wasn’t in Gillian’s gift, but making sure that the information on what mattered was shared with people who could make the improvements was.

NHS Lanarkshire’s Keep Well Team Nurses had established links with the Gypsy Traveller community in Lanarkshire. They already carried out health checks, monitored blood pressure and diabetes, addressed issues of mental ill health and wellbeing and had built up a rapport with the community but they wanted to go beyond the medical needs they were trying to meet and to engage with the community to find out what really mattered to them.

Two years ago through the Keep Well Team’s established links and with support from the site manager Roy Overend, Gillian Ventura attended a KeepWell clinic where she met 14 members of the Gypsy Traveller community and asked the question, ‘What matters to you?’

It became clear that what mattered most to this community is something that most of us take for granted – access to health services. Specifically this included getting registered for Health Services – GPs, Dentists, appointments and communication

Gillian developed an easy read note of the meeting which was shared with all participants.

The output from the work was also shared with the Travelling Community Network and with Scottish Government to help raise the profile of the issues that matter to this community. An Action Plan *Improving the Lives of Scotland’s Gypsy/Travellers (2019-21)* was launched by Scottish Government.

The Person Centred Care Team at Scottish Government developed, with input from the travelling community, GP Registration Cards, pocket sized cards which promote the right of the holder to register at GP practices so that, no matter where they are, they know they can access GP services.

Gillian said: “This is not a quick job! Gypsy/Travellers enjoy and are proud of how they live – it’s the discrimination and lack of respect and resource that they get annoyed about the most. This lack of understanding from ‘settled people’ can make it harder to engage with them, rightly they think ‘why should this time be any different?’ Building relationships,

persevering and most importantly understanding their culture, will over time, pay off, ensuring better health and social care not just for this community but for everyone using local healthcare systems. At a time when Gypsy/Traveller culture is being compromised due to lack of site provision, it's important to me that their voices are heard."

‘What matters to you?’ in an ICU during COVID-19

Dr Constantinos Kanaris, is a Paediatric Intensivist, who has been looking after critically ill children for the last 15 years in a Paediatric Intensive Care Unit and used to winning the survival battle 9 times out of 10. This is an extract of a longer article of his reflections during COVID-19 which is well worth a read.¹

Every death affects us but we are proficient at facilitating a good death for those that we can't save; a good death is paramount for patients and their families, but don't underestimate its importance to healthcare staff.

Overnight we became an adult ICU staffed with healthcare providers trained to work exclusively with children. Working all day in PPE human interaction is different. We can't read faces anymore; we can't see the smiles, the winks, the frowns each of us wears; non-verbal communication can signal most things, worry, elation, relief, the works.

A tsunami of COVID-19 admissions hits and the comfort of our 9/10-survival rate in children is gone, we are looking at survival rates of 5/10; on a good day. Days away from my family morph into weeks; I lie in a sterile hospital room with no windows.

What kept us awake at night during the pandemic was moral distress; the thought that somehow we were complicit in allowing these patients to die alone. Alone, without their loved ones being able to say goodbye due to social distancing, visiting restrictions and PPE shortages for non-clinical personnel. Medication is a poor substitute for a human, familial touch.

There had to be a better way. So we reached out to twitter.

The idea was to start compassion ward rounds on the ICU where a doctor alongside a family liaison nurse would videoconference a family member daily, at a predetermined time so they can see and speak to the patient. During the end-of-life families would get the chance to say goodbye remotely. Medical twitter didn't disappoint. Doctors, nurses, health professionals from far and wide weighed in within minutes. Soon we had a template for our battle-plan: a patient directed questionnaire that had already been developed to address the issue of patients dying alone². We tweaked it to account for subtle cultural nuances and make it more legally robust. It was then presented to the hospital legal ethics committees; given the timeframe, gravity of the situation and people dying alone the questionnaire was ratified within a week.

¹ <https://link.springer.com/article/10.1007/s00134-020-06194-0>

² The original Questionnaire recommended to me was designed by the Behaviour.Health Team and can be found here <https://drive.google.com/file/d/1YFTUmodSlx8eBmsodOLqWEPHnK2UPH5k/view>

The questionnaires were used across the hospital for adults with COVID-19 symptoms and enabled us to tailor end-of-life care, if necessary, based on their belief system, religion, musical and literary preferences. It wasn't perfect but it was better than dying alone. Within a week, word spread across the region and various charities donated 250 tablets to the hospital for this purpose alone. To be used to help patients communicate with their families. We translated the questionnaires in a number of languages to ensure there was no discrimination against ethnic minorities; the compassionate revolution was up and running.

Mrs X arrived to our ICU, already hospitalized for a week and deteriorating now needing critical care. The consensus was that her chances of survival were bleak. She had limited use of English and hadn't spoken to her family in 10 days. Imagine the fear these patients experience: fighting for their lives, on a ventilator, on inotropes, unable to understand the spoken language, unable to communicate with us. Terrifying.

Mrs X was one of the first patients to pilot compassion ward rounds. The first time she heard her daughters voice over a video call, in her own dialect, there were tears of joy. Not just from Mrs X but everyone else on the unit. From that point on she was galvanized. We mistakenly calculated that Mrs X had odds stacked up against her, the critical care abacus rarely lies; no one told the patient about it. A week on she was wheeled out of ICU to a general ward. On her way out, she summoned the strength to whisper something to me in her own language with tears in her eyes. I can never be sure of what she said but I suspect it was an expression of gratitude.

We cannot deny the impact that compassion has on our moral distress; nor can we deny the impact it had in giving this patient her fight to survive back. Compassion rounds had done their job. That night I had no trouble sleeping. The next day, I wanted to be a doctor again.

How Fife Women's Aid adapted how it connects during Covid-19

As an organisation continuing to deliver a service during the Covid-19 pandemic to women and children experiencing domestic abuse, Fife Women's Aid has had to develop new ways of maintaining contact. It was important to ask people what was important to them during the lockdown and to adapt and respond appropriately - this has included face to face contact for essential visits and remote contact through online means.

Lockdown has meant an increased demand for refuge and new refuge accommodation was needed to be able to meet some of this need. Working in partnership with Fife Council has enabled this to happen. Strong partnership working has provided a foundation for responding to meet the needs of families during lockdown.

The organisation has had to adapt to remote working, including making sure the correct IT infrastructure is in place as well as ensuring communication and support for staff is in place while working differently. One example of this is that prior to lockdown, group work for women had been offered but many faced barriers to participation, such as transport and travel, the use of virtual group work removed these barriers and demand has far exceeded that of face to face sessions.

But...how do you make sure a vulnerable client can be connected?

Awareness of the impact of lockdown for families experiencing domestic abuse has highlighted the significance of digital exclusion. This has resulted in tangible changes taking place quickly, such as installation of internet access in refuge accommodation and the provision of equipment for families where this was a barrier to participation. This was essential for children who were required to continue their education from home as well as for women to maintain contact with key people, such as family and professionals providing support.

Generous donations were received from the local community and organisations, including the University of St Andrews and local Fife Rotary Clubs in Fife and also the Scottish Government which allowed the purchase of IT equipment. Additional funding received allowed the provision of tablets for families where needed.

Children First, East Renfrewshire

During Covid-19 and the subsequent restrictions, the way Children First works with families in East Renfrew changed. Door step conversations have become part of the working week but it feels like this change has not always been a backward step. In some ways it has helped workers to get to know the families better and conversations have turned to what really matters in the here and now.

An example was shared where a single parent confided in her worker through the doorstep conversations, that she was very anxious about being able to celebrate her son's birthday during lockdown. She also shared information on financial worries, fuel poverty, family feuds and unresolved loss but also that she loved cleaning, baking and drawing. Over the next few weeks a plan to celebrate the birthday was devised which included her baking cakes and decorating with her drawings and at the same time an allocated worker was also working with her to unravel the financial and relationship worries.

On the day of the party her worker, who was dropping off a card and gift for her son, saw that the mother was seriously upset and panicked as a result of the unexpected appearance of an older and violent relative with whom there is usually no contact. Her worker immediately sat down on the ground with her, focussing on her breathing and talking about all the positive things she had shared with her over the last few weeks.

Children First places a great emphasis on compassionate connections but nonetheless the worker feels that they would not have had the confidence to do this with the client before lockdown but it just felt right at that time. While the history that the mother had shared showed very little experience of compassion in her life, she really wants to make sure that her son has a different story to tell. The conversations and hard work between the mother and her worker allowed the mum to say and do what really mattered to her at that time and have a good celebration for her son's birthday.

Every interaction and conversation potentially has more impact in these circumstances, and it's important now and always to connect in ways that make a difference to people. Every conversation counts- this was always true- but lockdown puts a spotlight on that for all of us.

6 Key learning and next steps

Each year following each 'What matters to you' day, we take time to reflect on how to maximise the impact in the following year so that more people can benefit thinking about and acting on this important question and in 2020 this is more important than ever.

In previous years feedback was sought from people who registered with us to participate but this year we did not have that option. The working group discussed what could be done differently in 2021 to support teams and individuals if we continued working under similar conditions to those of 2020.

It was agreed that a refresh of the WMTY website would be progressed. Success with the message of WMTY means that the focus is able to move from a single day to WMTY being part of the way that we work every day and the new website will reflect that. We will also build the website to have more functionality for users and link to the new WMTY World global network site. This will be undertaken with involvement of and feedback from users.

Planning ahead is difficult, but working on the assumption that there will still be some restrictions in place in 2021, a range of digital engagement activities are planned to highlight that now more than ever it is important to ask people "What matters to you?" and to listen and act on the answers.

There was a recognition this year that being physically present with those we care about was not always possible or indeed desirable and much of our interaction moved to online platforms. Whilst the move to engaging online became a necessity during 2020 and cannot replace face-to-face interaction, it has presented us with some opportunities for future WMTY work.

Person-Centred Visiting was already in place across NHS Scotland however, during the COVID-19 pandemic, visiting to all hospital wards was suspended except in end of life and other exceptional circumstances. For the majority of patients this meant they had no access to family, friends and loved ones throughout their stay in hospital. Patients in intensive care or critical care units or who were admitted in an emergency may have no access to mobile phones or other devices to enable them to stay in touch virtually whilst many others do not own such devices.

Person-Centred Virtual Visiting, as it is now known, began when staff realised that what really mattered to their patients was contact with their families and loved ones. They assisted patients to use their own devices and often used their own personal phones to connect patients and families. This led to fund raising to buy electronic devices for their own

wards, quickly followed by private companies donating devices and health boards investing in electronic devices to support Virtual Visiting.

It is intended that the Virtual Visiting service will complement Person-Centred Visiting across the NHS in Scotland and this will be an important legacy of the response to the COVID-19 pandemic, to help people stay connected if their visitors can't be there in person.

As we reflect on our essential question of "What matters to you?" the answers for 2020 were variations on the theme of family, loved ones and friends, on being able to be in contact with them, keeping them healthy, supporting them and just generally making sure they were okay. People said they felt a greater sense of community and care for other people than they can remember happening before. A greater sense of things being done to help others.

The stories in the media ranged from the incredible work of Captain Sir Tom Moore raising millions of pounds for the NHS, to local stores helping to ensure that families had enough to eat, hotels opening as accommodation for the homeless, as well as innumerable individual acts of kindness unseen behind the scenes every day. People going the extra mile to understand what mattered, to understand what was needed and then acting. Sometimes what was needed was a listening ear and a friendly face and other times much more.

The 'What matters to you?' ethos has influenced many other programmes of work across Scotland and there are a number of examples of where a focus on the things that really matter has positively influenced our work. We have listed some of these below:

Connecting Scotland – During COVID-19 the ability to be online was essential and Connecting Scotland is working to give every citizen in Scotland the kit, confidence and connectivity to get online.

Person Centred Care in COVID-19 – work undertaken by Healthcare Improvement Scotland showed that across all settings, there was a sense of shared values and that doing what was right for the individual was the priority.

Personal Outcomes Network (PON) - exists to promote a focus on what matters to people in health and social care in Scotland. One of the members noted that during COVID-19 they found it has been much easier to focus on what really matters to the residents in part due to the reduction in footfall through the care home.

Person-Centred Virtual Visiting – allows patients and service users to connect with their loved ones using tablets and smart phones through WhatsApp and FaceTime. It supports person-centred care and complements person-centred visiting, it can also support good mental health and wellbeing, reduce stress and anxiety for the patient or service user and

their loved ones and it can reduce social isolation. It can also reduce the number of calls a ward receives from relatives and frees up staff.

Two different, but connected reports, which asked WMTY questions related to peoples' experience of the Covid-19 pandemic and what their priorities for the future were now, have recently been published. These were Healthcare Improvement Scotland, Community Engagement's Citizen Panel report on health and social care experience during the COVID-19 pandemic and priorities for health and social care in the future³ and Health and Social Care Alliance Scotland's report Health, Wellbeing and the Covid-19 pandemic; Scottish Experiences and Priorities for the Future⁴. The content of both these reports will be used to inform the re-mobilisation plans for health and social care services across Scotland.

We have seen examples of evaluation and feedback and a common theme which runs through many is the desire not to lose the progress made and the ability to act quickly when needed. That is a challenge that will hopefully be accepted.

³ <https://www.hisengage.scot/informing-policy/citizens-panel/seventh-panel-report/>

⁴ <https://www.alliance-scotland.org.uk/people-and-networks/wp-content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Executive-Summary.pdf>

Appendix 1 – Working Group 2019-2020

Diane Graham	Improvement Advisor, Healthcare Improvement Scotland
Jennifer Rodgers	Deputy Nurse Director, NHS Greater Glasgow & Clyde
Louise McFarlane	WMTY Co-ordinator, Healthcare Improvement Scotland-Community Engagement
Parveen Khan	Equalities Mainstreaming Officer, CEMVO
Shaun Maher	WMTY Chair, Strategic Advisor for Person-Centred Care and Improvement Scottish Government
Susan McLaren	WMTY Administrator, Healthcare Improvement Scotland-Community Engagement
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Tommy Whitelaw	National Lead for Carers and Outreach, Health and Social Care Alliance Scotland
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