



**Isle of Man
Government**


Reiltys Ellan Vannin

Autism Service User Feedback

Care Pathways and Service Delivery Transformation Project

Health and Social Care Transformation Programme

December 2020



The independent health and social care review by Sir Jonathan Michael in 2019 concluded that our Island is well placed to become **a model of how to deliver a fully integrated health and care system**

The review concluded that we need to deliver:

- High-quality, efficient services
 - Proven best value
 - As locally as appropriate
- Timely provision of services, which are both accessible and integrated with other aspects of the system
 - A system that's both financially and clinically sustainable

Sir Jonathan Michael's report included a package of 26 recommendations to achieving a financially and clinically sustainable, high quality health and care system for the Isle of Man

Tynwald has for the first time committed dedicated resource – from financial to people – to work together to deliver on these recommendations with the Health and Care Transformation Programme

Health & Social Care Transformation Programme

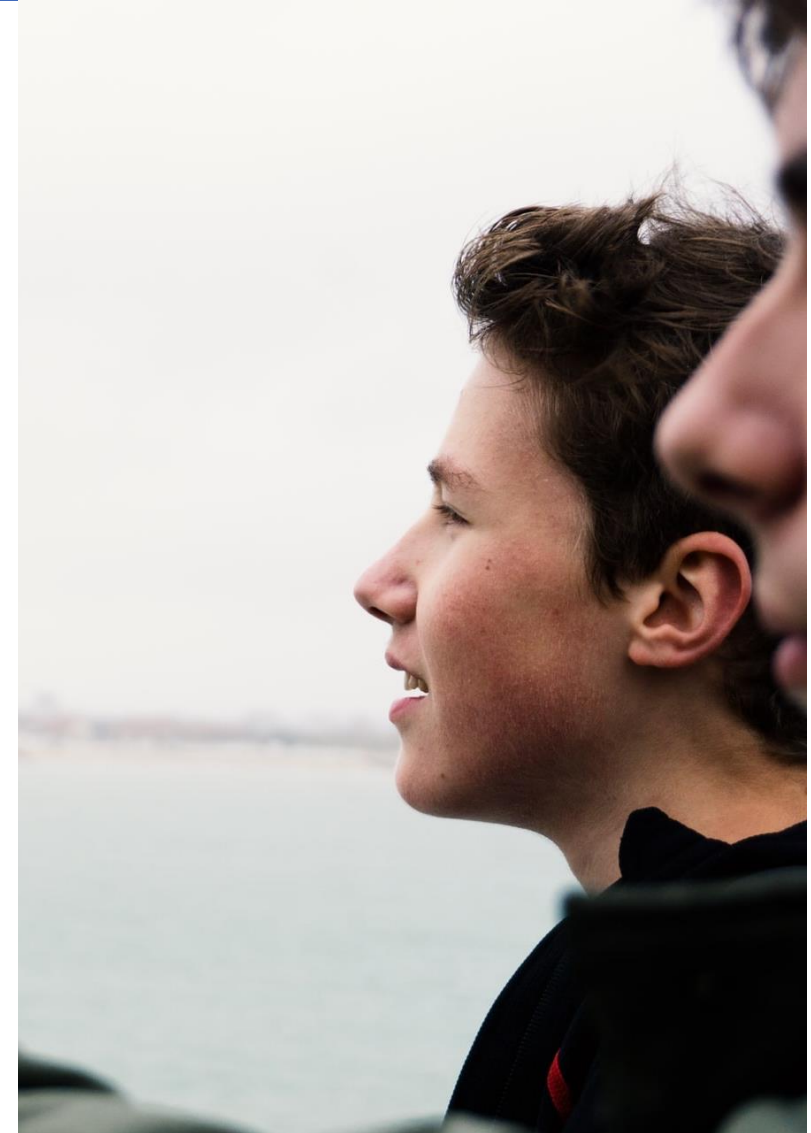
The Health and Care Transformation Programme is delivered by the Cabinet Office's Transformation Programme team in collaboration with the Department for Health and Social Care and Treasury (DHSC).

Our role is to bring long term and systematic transformation to our health and care system, in order to deliver high-quality, accessible and affordable health and social care services for every individual.

To achieve this, we:

- Engage with Service Users to ensure Service Users are at the heart of the improvement process
- Bring in colleagues from across the public service - particularly health and care professionals - to input, co-create and help us deliver our work
- Ensure that our focus on systematic change is aligned and working alongside other changes being delivered by the DHSC

The Service User Feedback summarised in this pack has been gathered as part of the Care Pathways and Service Delivery Project (Pathfinders)



Care Pathways and Service Delivery Transformation (Pathfinders)

This project will identify how we can improve the way services are delivered, now and in the future.

The project takes a pathfinder approach and has three parts:

- Needs assessment*
- Service-by-service review
- Integrated Care Pathway

The project team are starting with a focus on seven service areas:

- Diabetes
- Cardiovascular conditions
- Urgent and Emergency Integrated Care
- Cancer
- Eye Care
- Children with Complex Needs
- Autism

Progress update:

- Stage 1: completed in August, this focused on desk-based research into Isle of Man needs for each service, reviewing best practice and developing an 'ideal' model
- Stage 2: through interviews, surveys and workshops we are gathering views on 'ideal' service and mapping out what is needed to achieve it
- We have held workshops with service users and their families/carers, service providers and health and care professionals. These will continue for the rest of 2020.

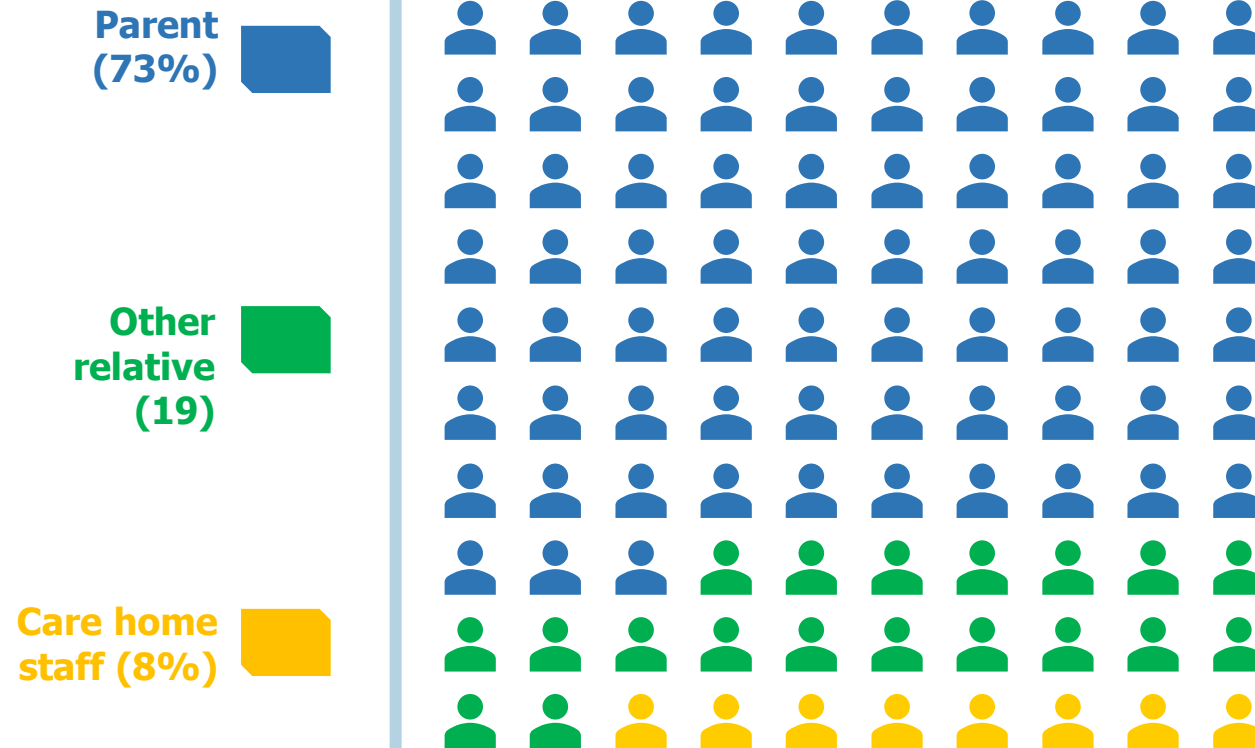
*In September 2020, it was agreed that the Needs Assessment project would be reinstated as an independent project to Service-by-Service reviews to enable medium to long term needs assessments

Service User Questionnaire Feedback



Autism service user feedback – demographics

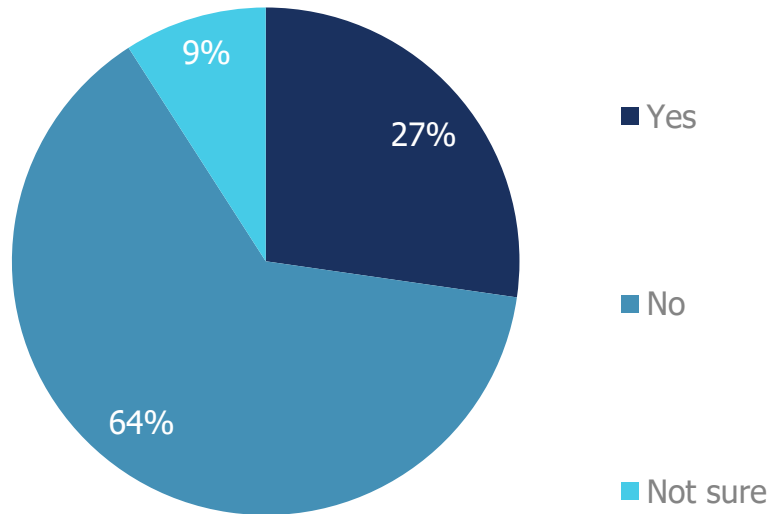
Out of **33** responses: 5% of the surveys were completed by people with autism, and 85% by other people, including:



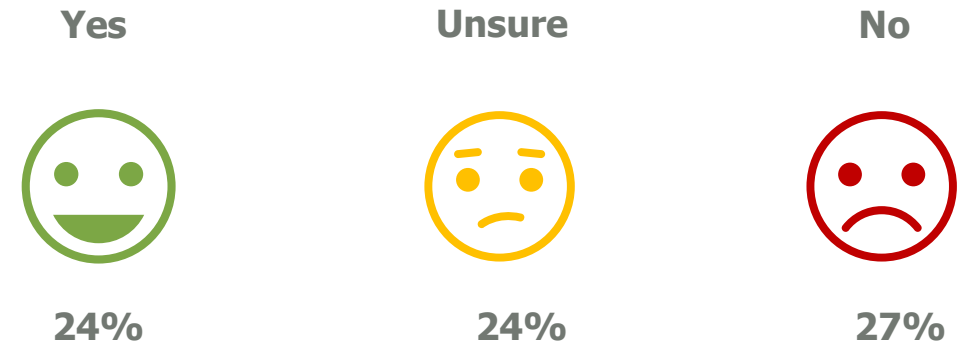
NB: percentages may not add up as some questions were left unanswered

Autism service user feedback

1. Do you have a care plan?



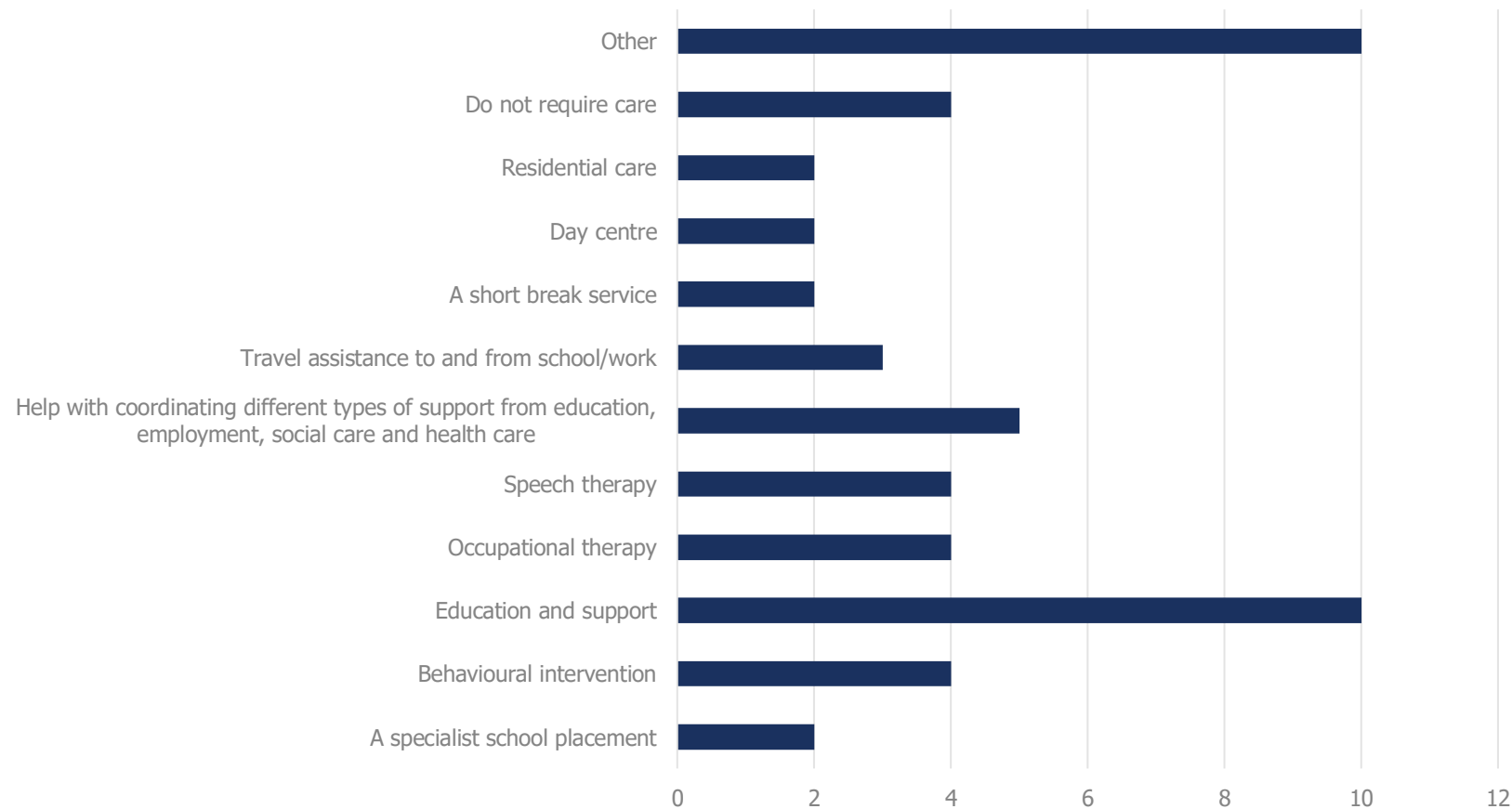
2. Were you happy with the level of involvement you or your carer had in developing your care plan?



The remaining 25% do not have a care plan or were unable to get one.

Autism service user feedback

3. What does your care currently look like?



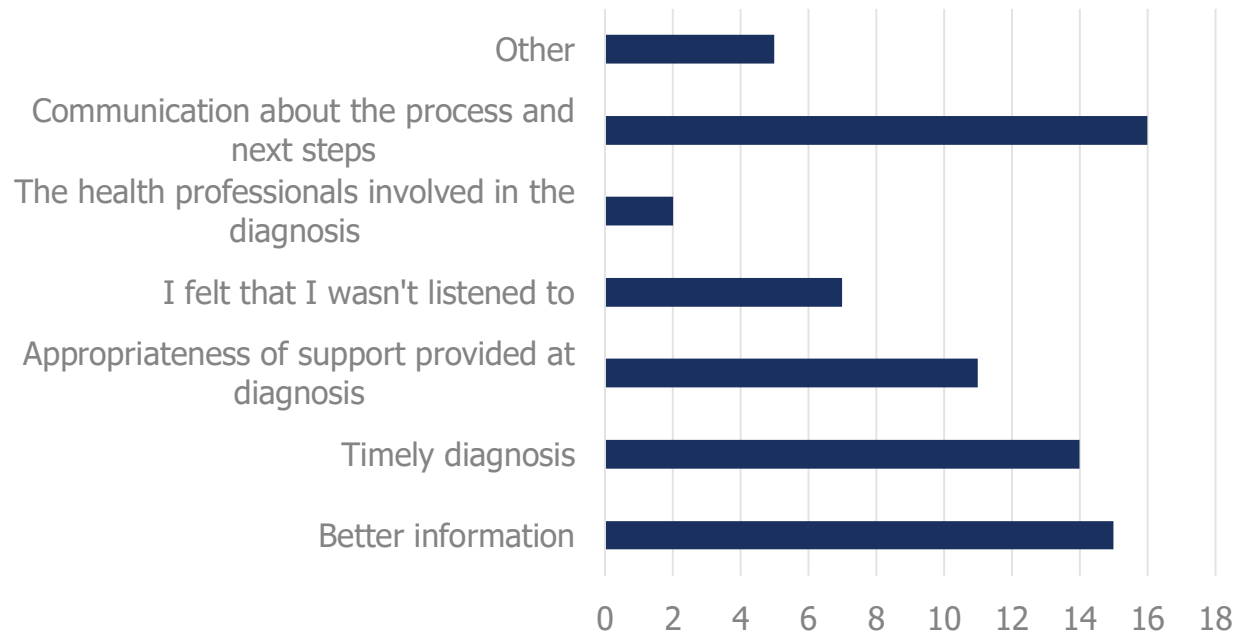
'Other' included individuals home-schooling their children due to Covid and the lack of online resources and people who do not have a care plan.

Autism service user feedback

4. Were you satisfied with the level of care, information and support you received at diagnosis?



5. What would you have changed or found helpful?



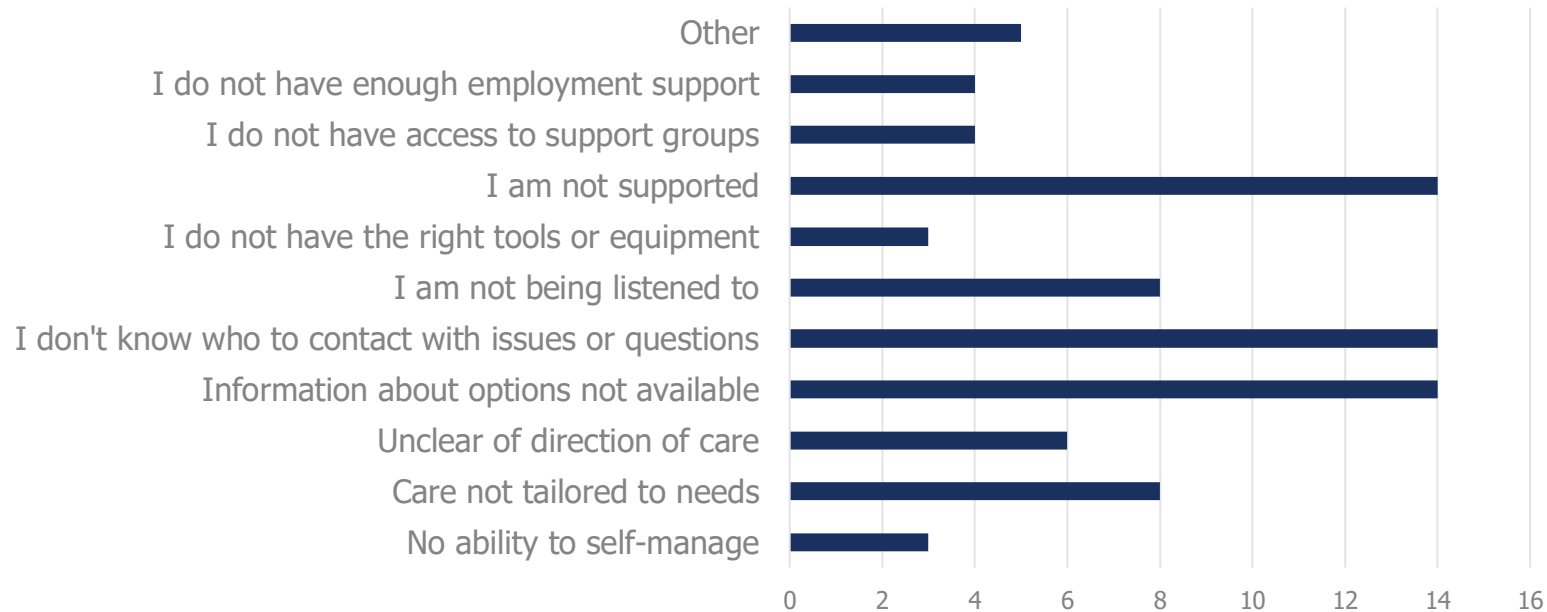
'Other' included advice and support for the child, parents and family members, as well as signposting to support services once diagnosed.

Autism service user feedback

6. Are you satisfied with the level of care, information and support you receive now?



7. What is missing that would be helpful?



'Other' included lack of SALT input, gender identity counselling, inability to access any services and those that did not have a care plan

Autism service user feedback

8. If you have a healthcare plan, do you know what outcomes/goals you are trying to achieve?



Yes

24%



No

6%



Unsure

15%



Does not apply

55%

9. If you are under 19, have you discussed transitioning to adult services with your key worker/any relevant professional?



Yes

0%



No

29%



Unsure

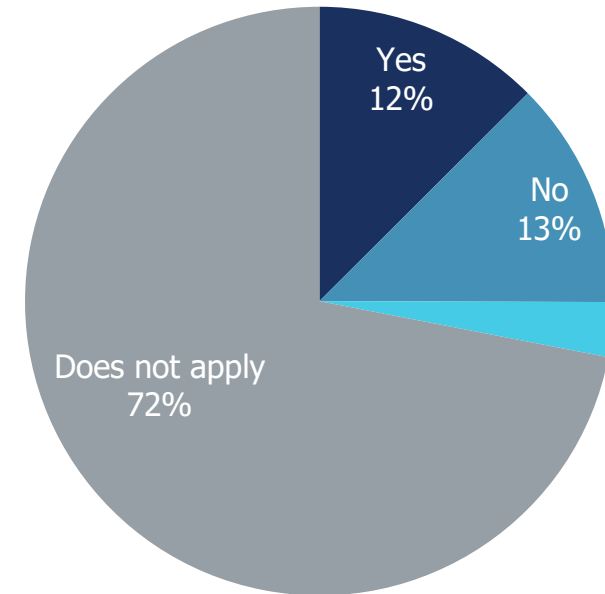
6%



Does not apply

65%

10. If applicable, were you satisfied with your transition to adult care services.



■ Yes ■ No ■ Unsure ■ Does not apply

Autism service user feedback

11. If applicable, are you currently employed?



12%

Yes



33%

No



55%

Does not apply

12. Do you know how to access help if needed or who to call for information and advice?



34%

Yes



3%

No, I don't require additional help



63%

No, but I would like to know

Service User Interviews Feedback



Service user interview - key themes

Lack of communication

Lack of support for families and carers

No support until crisis

Those who shout the loudest

Delayed planning

Poor continuity of care



Next Steps

What happens next

Pathfinder Engagement Process



We'd love to hear your thoughts...

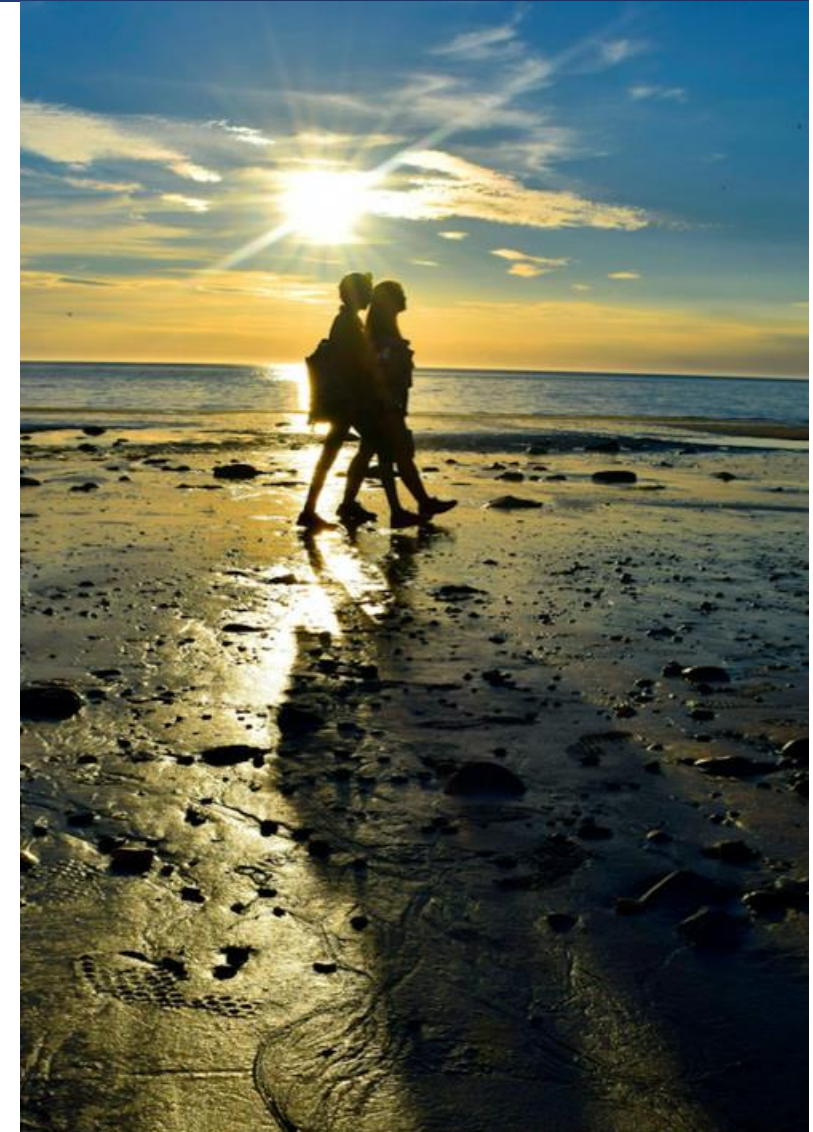
Contacts:

Health and Social Care Transformation Programme

- If you have any questions, comments or other feedback regarding the work being done to the Health and Social Care Transformation Programme team at:
 - HealthandCareTransformation@gov.im

Care Pathways and Service Delivery (Pathfinders) Transformation Project

- If you have questions that are specific to the Care Pathways and Service Delivery Project (Pathfinders), including any related to the Pathfinder Engagement Process or the Service User Feedback findings summarised here, please contact one of our team:
 - Project Lead – Claire Bader
 - claire.bader@gov.im
 - Project Manager – Francesca DeHaven
 - francesca.dehaven@gov.im



Working together, we all want to create a sustainable system that:



improves quality of care



organises care around patient and service-user needs



delivers the right care, in the right place, at the right time, in the most affordable way

