Appendix: Consultation response form

Respondent information

Name	Rachel Le Noan (Policy Officer)
Organisation name (if applicable)	Down's Syndrome Scotland
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Please return this form by 7 February 2014 to: hcis.DrivingImprovement@nhs.net

1	We are a statutory body that works with healthcare providers to drive improvement in the quality of healthcare, and empowers patients and the public. We do this through a unique combination of evidence-based standards and guidelines, a scrutiny and assurance approach that is fair but challenging, and quality improvement implementation support. (page 6, 'who we are') Do you agree with the organisation's approach to driving improvement which combines evidence, scrutiny and assurance, and quality improvement?
	Yes
	Do you have any comments on the merits or disadvantages of our approach?
	Down's Syndrome Scotland strongly supports the statement indicating that the people of Scotland have a right to expect safe and effective care and a right to be informed and involved about their care and treatment. We believe that any patient should be able to make informed choices and be supported in making decisions about their care.
2	Our mission: to be the recognised healthcare improvement organisation which drives the delivery of world-class, person-centred healthcare with and for the people of Scotland. To continually seek out innovative opportunities to ensure high quality healthcare for every person, every time. (page 6)
	Do you agree with our stated mission?
	Yes
	Do you have any comments on our mission?
	To have a single organisation in charge of healthare improvement would be a significant advantage. As of now, with regard to delivering services, we know that issues about the lack of communication between public bodies and/or the absence of consistency across the country can result in stressful situations for some of our members. Having a unique 'go-to' organisation like Healthcare Improvement Scotland (HIS) would thus be a great improvement.

Our key organisational priorities for the next six years are to:

- Empower people to have an informed voice that maximises their impact in managing their own care and shaping how services are designed and delivered
- Reliably spread and support implementation of best practice to improve healthcare, and
- Comprehensively assess the quality and safety of healthcare. (Page 7)

Do you agree with our key priorities for the next six years?

Yes

Do you have any comments on our key priorities?

- Empowering people to manage their own care and to shape how services are delivered is a strong commitment that Down's Syndrome Scotland fully supports. By listening to the voices of patients and ensuring that staff delivering services are also appropriately trained and informed about their work, more patients will be able to make an informed choice about their care.
- Down's Syndrome Scotland is of the view that involving third sector organisations is key to gather relevant examples of best practice. We also know that by developing relationships with the third sector, HIS would benefit from a wide range of knowledge and experience that would lead to the delivery of better services and care. With regard to that specific point, we would therefore welcome further indication on how guidance issued by HIS may be monitored and on the resources available for this. Indeed, the provision of guidance and robust advice is likely to be less relevant if these are not fully taken into account and correctly implemented by NHS Boards across the country.
- The issue of monitoring is also pertinent with regard to the third priority
 which focuses on comprehensive assessments of healthcare. Again we
 would encourage HIS to provide further information as to how the
 scrutiny of NHS services is performed and how the voices of patients
 will be included in such assessments.

On pages 8-13 we have set out what we will do to continually improve how we deliver our priorities.

Do you feel these are the correct areas of focus?

Yes

Is there anything missing? Is there anything you feel is less important?

Down's Syndrome Scotland supports the values and priorities put forward by HIS in its strategy. Since the values of teamwork and working in partnership appear to constitute key priorities, we would encourage HIS to make reference

to the necessary involvement of third sector organisations earlier in its strategy. The document refers to 'other agencies' on page 9 or 'multidisciplinary teams' on page 10 but a direct reference to the role of the third sector is only made on page 13. Down's Syndrome Scotland argues that the knowledge and expertise that can be found in third sector organisations could undoubtedly help HIS to achieve its priorities by 2020. Involving the third sector from an early stage would also give more leverage to HIS to deliver its priorities because the organisation would then be able to rely on the experience of a wider range of partners.

Regarding issues of 'evidence' and 'scrutiny and assurance' as presented on page 10, once again more evidence could also be gathered through third sector organisations. Indeed, in our experience, patients may not always complain to NHSScotland about the services they receive in hospital but they would do so with the charity they are a member of. Raising concerns about health services can be stressful for parents of a newborn baby for example, and it is important to consider that it also constitutes a time-consuming and harrowing process for new parents. Parents' views however ought to be considered and that is the reason why involving the third sector throughout the whole process is essential as it will enable HIS to gather better information and more accurate data and thus inform NHSScotland about necessary changes.

On page 10, it is also argued that HIS produces information in a variety of formats to support patients, carers and healthcare professionals. As a charity, Down's Syndrome Scotland currently provides 'baby packs' to maternity units throughout Scotland however we are aware that new parents are not always given this information which could be very helpful to them. As a result, we would welcome any steps taken towards ensuring that patients receive all the information they need. We would encourage HIS, as part of their monitoring programme, to ensure that materials like 'baby packs' are appropriately stocked in hospitals, midwives community centres etc and delivered to patients when needed.

5 To continually improve how we deliver our priorities, we will... be the 'go-to' organisation for improvement expertise within the healthcare sector and bring our knowledge, skills and expertise in improvement science closer to the service through greater local and regional collaboration (page 11) Do you see Healthcare Improvement Scotland as the 'go-to' organisation for improvement expertise in healthcare? Yes/No If not, are there other organisations / sources of expertise you would consider first? Our strategy is based firmly on the values that are shared across 6 NHSScotland (as set out in the 2020 workforce vision): - care and compassion - dignity and respect - openness, honesty and responsibility - quality and teamwork (page 9) Do you agree with our stated values? Yes Do you have any comments on our values? 7 There are many health and social care bodies working in Scotland to deliver the 2020 vision for health and social care in Scotland. As a public body we contribute to securing the value and financial sustainability of Scotland's health and care services. We do this by increasing our efficiency and productivity in order to make best use of resources. We also positively impact on the value and financial sustainability of the health service through our evidence-based advice and guidance on the clinical and cost effectiveness of health technologies, medicines and service redesign. Our main focus as a healthcare improvement organisation is to **drive** improvement in the quality of healthcare, working with healthcare providers. (page 18) What do you see as the most important contributions Healthcare Improvement Scotland can make to achieving the 2020 vision for Scotland?

To achieve its 2020 vision, Down's Syndrome Scotland believes that HIS's most important priority should be to listen to the voices of patients. Bad and good experiences can then be translated into recommendations for NHS Scotland that will ensure that healthcare services are truly person-centred. We also consider that a good quality of healthcare can only rely on staff who are well-trained and informed about conditions like Down's syndrome. As a charity, Down's Syndrome Scotland provides training to professionals across Scotland and, for example, we would be happy to consider opportunities to work with HIS in providing more training sessions to NHS Boards in order to achieve Scotland's 2020 vision for health and social care.

In addition, the support HIS may give to partnerships and projects should also be considered as a relevant contribution towards improving healthcare in Scotland. Down's Syndrome Scotland is currently working with Jane Reid (AHP National Lead for Children & Young People) as part of a working group, looking at the role and support offered by Allied Health Professionals (AHPs) to children with Down's Syndrome and their parents/carers. It is hoped that this work will lead to the development of a nationally agreed 'Down's Syndrome Specific Care Pathway' which all Health Authorities and AHPs will adopt. Once published, the successful implementation of this care pathway would undoubtedly benefit from the support of HIS who, as a leading organisation, could monitor the extent to which the new guidelines are being followed.

Finally, another significant contribution that HIS can make is to encourage NHS Boards to plan for the future. People with Down's syndrome are more likely to suffer from early onset of dementia because of their condition and it is crucial to make sure that all those concerned receive the right level of care when they need it. In our opinion, planning for the future is essential and should also become a key recommendation that HIS helps implementing to ensure that future needs are met and that NHS services remain personcentred by 2020 and beyond.

Are there any questions, issues or opportunities arising from this strategy document?

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