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Dementia 100: Pathway Assessment Tool

Hints and Tips & Frequently Asked Questions



Hints and Tips

We recognise every Integrated Care System and Place is different, with wide ranging services on offer, multiple relationships across partner organisations and varying population demographics. Here are top hints and tips from piloting the Dementia 100 in four Integrated Care Systems for your consideration as you complete the toolkit in your area:

Partnership working is key

Embed effective partnership working throughout the completion of the Dementia 100, from preparation to using the insights in your area once completed, including with people living with dementia and their carers. Bring partners together, seeking a range of voices to give you a balanced, realistic view of the current position and help increase visibility of any blind spots, hidden strengths, good practice and opportunities for the future. Completing the Dementia 100 is an opportunity to reflect together on areas you may not have previously discussed in detail together before, bringing to the surface new opportunities to collaborate.

Take the time to prepare in advance

Effective preparation for the completion of the Dementia 100 can streamline the process and ensure you are engaging with the right stakeholders from the start for each pillar and criteria. Use the preparation time to share the purpose of the Dementia 100, the difference it can make to people living with dementia and carers in your area, their role to play in contribution to the Dementia 100's completion. Consider how best to bring partners together such as asking each partner to review the Dementia 100 separately before coming back together to discuss each perspective or agreeing the scores together from the start. Some colleagues may be unfamiliar with acronyms, service names or there may be some terminology colleagues use differently therefore seek a shared understanding. The glossary in the Dementia 100 Full Implementation Guidance is a good starting point for you to use together.

Have clarity on roles, responsibilities and governance

Agree and consider specific roles to help lead and coordinate the timely, accurate and inclusive completion of the Dementia 100. Ensure there is appropriate governance to support the completion of the Dementia 100 and to monitor and support where partners may be struggling. If there is a Dementia Steering Group (or equivalent) this could offer a good multi-disciplinary space for this to be monitored.

The following example roles could be adapted to best meet the needs of your system or place:

- **Senior Sponsor(s)** to approve and champion effective partnership working to complete the Dementia 100 across the System and/or Place.
- **Overall Dementia 100 coordinator / lead for a System**, with oversight and coordination of the completion of the Dementia 100.

- **Overall Dementia 100 coordinator / lead for a Place**, with oversight and coordination of the completion of the Dementia 100 within a Place, such as collating information and engaging with partners.
- **Pillar coordinator / lead** (across a single or multiple Places) based on their specific area of focus such as from a Local Authority or NHS organisation to coordinate the completion of their assigned pillars and ensuring inclusion of all relevant parties.
- **Independent Facilitator** from within or outside of the System or Place to assist moderating harmonised scores, if/as necessary.
- **Support** on administrative activities such as organising meetings to discuss specific pillars and sharing communications.

Think about timescales

Consider the timing that will work best for your System and Place (e.g. avoiding holiday periods) as the completion of the Dementia 100 will be in addition to all partners' day to day activities. Be realistic on how long it will take for partners to collate the information needed to score each criteria whilst being ambitious to have a harmonised Dementia 100 within a reasonable timeframe so the insights can be turned into timely and valuable improvement actions.

Effectively manage different perspectives

Every partner may bring different experiences, knowledge and ideas therefore it's important to listen and respect different perspectives. Agree up front how you will manage any difference in opinions on the scores, for example through a moderation session led by an independent colleague and an agreed lead to ultimately make a decision based on the available evidence. Consider discussing and agreeing all scores in a meeting together rather than through emails as this enables differences to be identified and resolved more easily together. Share evidence to support different perspectives and where appropriate seek out additional evidence to help build a consensus.

Be pragmatic

Remember, this is not an audit, it's for the Systems and Places to use to identify key gaps and opportunities to inform planning. After completing the Dementia 100, if partners have had in-depth discussions and learned more about each other's perspectives then the Dementia 100 will have had a positive impact. For that reason, don't spend too long completing a 'perfect' Dementia 100 at the expense of working together to improve outcomes for people living with dementia and their carers. There may always be more evidence that could be gathered so it's important to have a cut-off point where a score can be decided using the information available at that point. When completing the Dementia 100 think about local nuances and interpretation and refer to the supporting information section in the toolkit or check the guidance document if you're unsure.

Be evidence-based and inquisitive

Keep focused on this as an evidence-based toolkit and use the availability of evidence to drive your decision making. Seek more information such as data or views from other stakeholders to gather more perspectives. Sharing evidence and examples will inform the rationale for criteria scoring, based on an accurate reflection of the current provision in place and help spread best practice across the System. Evidence will assist in challenging assumptions, understanding gaps in knowledge and spotting potential trends. Take the opportunity of completing the toolkit to ask questions, be inquisitive, respectful, and collaborative in your approach to information sharing and assessment.

Proactively identify commonalities and trends

Whilst each Place may have specific nuances there may be some commonalities across the System and even Regions or Nationally. Being open to sharing your Dementia 100 findings, evidence and proposed actions across wider geographical footprints may help to coordinate joined up improvement activities and funding applications, help to explore identified trends, reduce duplication, spread good practice and understand common challenges.

Use the findings to make a difference

Throughout the process there may be several areas for development identified, therefore think about what is most important to your Place and System, what can be realistically improved in the coming year and what fits with your wider strategic objectives and plans. Once the priorities have been agreed embed the actions into Place and System action plans and strategies. Plan to review the difference made against your baseline Dementia 100 findings to track and celebrate your progress.

Frequently Asked Questions (FAQs)

1. [What is the purpose of the Dementia 100: Pathway Assessment Tool?](#)

The Dementia 100 brings together a set of standards which collectively describe the elements of leadership, prevention, diagnosis, care, treatment, and support considered to be best practice in the design and implementation of services provided for people living with dementia and their carers. It is a Place-based self-assessment tool that enables Systems to understand service provision to support their strategy and improvement work.

2. [How can completing the Dementia 100 benefit people living with dementia and carers in my Place and Integrated Care System \(ICS\)?](#)

Completing the Toolkit supports ICSs and Places to better understand any gaps, opportunities and good practice across all aspects of dementia care. Together partners can then prioritise their improvement actions and share good practice with other areas.

3. [How has the Dementia 100 been developed?](#)

The Dementia 100 has been in development for over two years and has undergone rigorous review, engagement, testing, and improvement to ensure it is fit for purpose across a wide range of systems and services. It has been aligned with new and emergent guidance including the Neighbourhood Healthcare Guidelines (2025/26), the Right Care Scenario for Dementia (2024), The High Impact Change Model for Dementia and Delirium (2024), the FRAIL Strategy (2024), and the Young-onset Dementia Pathway (2025). It is considered to be the next step from the Dementia Care Pathway (2018) and elicits pertinent NICE Guidelines and Quality Standards. People with lived experience and their families and carers have been involved in the work throughout. Charities that support those with dementia and their families have also participated in their development of the toolkit and guidance.

4. [Should the Dementia 100 be completed at an ICS or Place level?](#)

The tool should be completed at a Place level, taking into account neighbourhood nuances. The information can then be combined to give an ICS picture to assist in trend identification and the sharing of good practice. Once trends have been identified, priorities for improvement can be set and this can be used for strategy development.

5. [Who needs to be involved and engaged in completing the Dementia 100?](#)

Stakeholders should be involved who are able to share insight on the level of provision for each criteria. Stakeholders should have the detailed knowledge that will enable them to complete the criteria accurately and rapidly. Identifying the right people to take part in the tool's completion is a scoping exercise that is invaluable to both accurate and timely completion of the tool and to the opportunities for improvement at a later point in the process. A tailored approach is required as well as consideration of all relevant stakeholders in advance wherever possible in order to maximise the completion potential.

6. [What should I prioritise first when starting to complete the Dementia 100?](#)

Consideration should be given to the governance and coordination of the completion of the Dementia 100, such as securing senior leads to champion the work and identifying

Place-based leads to gather the scores from colleagues across the footprint. This will assist in the agreement of a shared approach to completing the tool that works best for ICS and Places with clear roles and responsibilities.

7. **What is my role in completing the Dementia 100?**

There are a number of potential ways to get involved in the completion of the tool, from senior leaders who sponsor the work, ICS or Place-based leads/coordinators or being a Place contributor depending on your subject matter expertise.

8. **Which criteria should I complete?**

All criteria should be fully completed to give a comprehensive, accurate picture of the current dementia provision across a Place. You may be asked to contribute your views and share evidence of the current provision for one or more pillars, depending on your subject matter expertise or perspective.

9. **How do I best gather the information to support the scores for each criteria?**

The Dementia 100 should be completed using an evidence-based approach. It's important to proactively seek out evidence and feedback to enable a score to be agreed for each criteria, challenging any assumptions or gaps in knowledge.

10. **What do we do if a Place or ICS structure is about to change, the delivery footprint is challenging to fit into a single Place toolkit or the Place would prefer to split their scores?**

It is important to maintain a Place-based approach to the completion of the Dementia 100 to encourage collaboration and system working and to avoid encouraging any silo working at Place level.

11. **Where can I get more information about the criteria and what good looks like?**

You can find a 'supporting information' tab in the toolkit which provides additional information such as useful links, guidance, and examples.

12. **Why does some of the criteria look very similar?**

Some differences in criteria may be subtle and are built into the Dementia 100 to increase visibility of different scores for similar provision within different settings, such as hospitals compared to in the community.

13. **What do we do if we do not know what the score should be?**

Consider any additional information that can be gathered and have conversations with any additional stakeholders to hear their perspectives. This is an evidence-based tool therefore should not be based on a perceived level of provision but what can be evidenced in practice. Ultimately, a pragmatic approach is recommended to agree a score based on the evidence available.

14. **What do we do if we cannot agree on what the score should be?**

Consider gathering additional evidence and feedback to gather further insights. A moderation session is key to be in a position to consider all perspectives and harmonise the data. It is recommended to agree as a Place and/or ICS from the start how any

disagreements that cannot be resolved by partners will be managed, such as an overall lead agreeing the final score based on all evidence available.

15. **What do we do if multiple scores apply to the same criteria within a Place due to different services being provided?**

Note the differences in level of provision and record the lowest score for the criteria.

16. **What if an organisation does not want to contribute?**

Seek buy-in from partners from the start to encourage participation and seek a range of voices to be heard within the process. Participation in completing the tool is not mandatory, though involvement from all relevant partners will help maximise the potential positive impact for people living with dementia and carers.

17. **Is the information shared anonymous?**

The Dementia 100 is for Place and ICS use and not for national reporting. The potential benefits will be reduced if information is anonymised as it is then more difficult to plan improvements and collaborate. To get the most from the Dementia 100, information should be shared in an open, comprehensive way to enable a shared understanding of gaps and good practice. If information is agreed to be shared more widely (such as with another ICS, region or even nationally) this will add an even greater understanding of the shared challenges and support wider collaboration.

18. **How can we share good practice we have found with others?**

As a Place and ICS you may agree to share examples of good practice you identify from the process with other Places, ICSs, regionally or nationally. This will assist in collaboration and enable other areas to implement your good practice for the benefit of people living with dementia and carers.

19. **How can we use this towards our future planning?**

As a Place you can identify the improvement priorities from across the criteria, which will be collated in the Dementia 100's 'Improvement Plan' tab. Work in partnership to embed these priority improvements within your activities and use the toolkit as a baseline to track and celebrate progress.

20. **Where can I go if I need more guidance about the Dementia 100?**

More information on the toolkit is available within the 'Full Implementation Guidance' document and training materials.