

ACT ON DEMENTIA

FINAL REPORT
SUMMARY VERSION

WORK PACKAGE 4 **Diagnosis and Post-Diagnostic Support**



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Contents

Acknowledgements	4
Act on Dementia.....	5
1. Introduction	6
Methods.....	7
Implementation pilot projects.....	8
2. Results from the Best Practice Model implementation projects	8
Best Practice Model 1. Anti-stigma project.....	8
Main message.....	8
Background and rationale	8
Objectives and method	9
Main results.....	9
Challenges	11
Key messages and next steps	11
Best Practice Model 2. GP–nurse co-operation project.....	11
Main message.....	11
Background and rationale	11
Objectives and method	12
Main results.....	12
Challenges	13
Key messages and next steps	13
Best Practice Model 3. Telemedicine pilot project.....	14
Main message.....	14
Background and rationale	14
Objectives and method	14
Main results.....	14
Challenges	15
Key messages and next steps	15
3. Conclusion and key lessons.....	15
Key lessons	16

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Act on Dementia

Act on Dementia is a 44-month European Union Joint Action which began in March 2016 and ends on 31 October 2019.

The aim of the Act on Dementia Joint Action is to promote collaborative actions among Member States to improve the lives of people living with dementia and their carers. It provides practical guidance for policy-makers developing and implementing their national dementia plans, policies and strategies, and provides cost-effective and practical examples of the core components of good dementia diagnosis, care and support.

Act on Dementia consists of seven work packages:

- Work Package 1: Co-ordination
- Work Package 2: Dissemination
- Work Package 3: Evaluation
- Work Package 4: Diagnosis and Post-Diagnostic Support
- Work Package 5: Crisis and Care Co-ordination
- Work Package 6: Residential Care
- Work Package 7: Dementia-Friendly Communities

For further information on the work packages, reports and other resources, access: <https://www.actondementia.eu/>

1. Introduction

Neurocognitive disorders (NCDs) remain widely underdiagnosed or are diagnosed late in Europe, and care management differs between countries.

Neurocognitive disorders

Neurocognitive disorder is a general term that describes decreased mental function due to a medical disease other than psychiatric illness. It includes dementias, but also dysfunction due to, for example, traumatic brain injury or injury due to lack of oxygen to the brain, insufficient blood supply to the brain, degenerative conditions and drug- and alcohol-related conditions.

The European Union Joint Action Act on Dementia (2016–2019) Work Package 4 (WP4) focused on identifying and improving:

- the situation of people currently living with NCDs and their caregivers; and
- best practices of health-care providers for this population.

WP4's main aim was to improve diagnosis and post-diagnostic support for people living with NCD through:

- collective reflections, active collaborations and agreements among international experts from several European countries;
- a detailed analysis of the currently available scientific literature and recommendations in this field; and
- the coordination and implementation of multi-site pilot projects.

Benefits and risks of NCD diagnosis

One of the major benefits associated with NCD diagnosis disclosure is preservation for as long as possible of the person's autonomy, safety and quality of life. It also maximises the person's involvement in decision-making processes.

Making an accurate diagnosis of NCD is essential to prescribing the most appropriate options for curable disorders and to prevent complications. Prevention and early symptom management must feature prominently in the diagnosis process, including prevention of iatrogenic consequences of inappropriate drug use.

Disclosure nevertheless is not without risks for the person. Beyond the negative psychological impact, there is significant risk of patient stigmatization and discrimination. Infantilization and early institutionalisation, often resulting in progressive loss of rights and skills, may also emerge as threats. The risk of false diagnosis is fairly limited for the major NCDs, but those with mild NCD are more likely to be subject to mis- and over-diagnosis.

Given the impact of an NCD diagnosis on the patient's and family/caregivers' lives, it is crucial to ensure a high-quality diagnosis approach, including access to a second medical opinion if needed. It is also essential to follow recommendations on how to communicate and the attitude to adopt (positive, constructive and compassionate). Communication and the choice of words used for diagnostic disclosure seem particularly crucial for patients, affecting their and their families' reaction. Established knowledge of the patient's characteristics is a valuable asset at such a delicate time.

On the basis of collaborations with the WP4 expert group and the main results extracted from a WP4 European survey, three main themes were prioritized for the pilot work:

- **the Anti-Stigma Project:** specific and in-depth training of health-care professionals, particularly primary-care providers, to amend opinions, attitudes and practices regarding NCD;
- **the General Practitioner (GP)–Nurse Co-operation project:** better detection and diagnosis of NCD in primary care; and
- **the Telemedicine Project:** better detection and diagnosis of NCD in specialist care settings, such as nursing homes.

A feasibility report summarising progress on each of the three themes in the implementation pilot project was presented to European Union Joint Action leaders and others in July 2018.¹ The second report was based on the main significant findings associated with the projects and presented their main conclusions and key messages, along with facilitators and barriers encountered during the testing phase and proposals and impact indicators for further complementary work. This report briefly summarises the findings.

Findings from the *Report on the Benefits & the Risks of Dementia Diagnosis* produced by WP4, from which the best practices tested in the implementation phase were identified, can be accessed from the Act on Dementia website.²

Methods

The WP4 working group applied the same methodology to all the pilot projects, testing proof of concept but also developing appropriate tools to meet the needs and issues related to NCD detection and diagnosis. This included:

- studying the existing literature to support the work, including a literature analysis of each pilot theme;
- performing a needs assessment analysis at national level for the countries involved in the work package;
- organising the work in project mode, with focus groups, regular monitoring and using the original tools to meet the individual needs of each project;
- identifying evaluation tools, such as impact indicators; and
- producing WP4 shared consensual key messages, including one main message for each pilot project.

This approach and all tools used are available in the original report.

The method was also also informed by the Hierarchized Diagnosis Strategy for Neurocognitive Disorders developed by WP4: to view an explanatory video of the Hierarchized Diagnosis Strategy for Neurocognitive Disorders 1, access:

<https://www.actondementia.eu/resources>.

¹ The report, *Preliminary Feasibility & Update Report on Testing Evidence-Based Examples of Best Practices in Detection & Diagnosis of Neurocognitive Disorders*, can be located in Appendix H of the original report.

² See: <https://www.actondementia.eu/sites/default/files/2018-02/Work%20package%20-%20Report%20on%20the%20Benefits%20and%20Risks%20of%20%20%20%20Dementia%20Diagnosis.compressed.pdf>

In addition, results of the European survey conducted by WP4 from April 2017 were considered to better identify the needs encountered in each partner country. This survey aimed specifically at governments, health-care professional associations and family and patient associations, asking about detection and diagnosis of NCD and associated post-diagnosis support from the perspective of each population.

Implementation pilot projects

Ten implementation pilot projects were conducted in the framework of the testing phase in 2018:

- **the anti-stigma project** was taken forward across four sites in three countries – two in France (Limoges and Lyon), one in Poland (Lublin) and one in Bulgaria (Sofia);
- **the GP–nurse co-operation project** was implemented in France (Lyon), Italy (Modena) and Bulgaria (Sofia); and
- **the telemedicine project** was carried out in France (Bordeaux), Greece (Athens) and Bulgaria (Sofia).

The WP4 leader team provided regular monitoring and ongoing support throughout the testing phase and provided many tools and documents required for the construction and development of the individual Best Practice Models implemented in test sites, including preliminary and satisfaction questionnaires, Excel databases and administrative documents related to ethical and regulatory issues. The team also ensured centralised management of all data collected during the pilot testing phase.

Coordination of the implementation projects was supported by two meetings, the first (opening meeting) held in Paris, France in November 2017 and the second (closing meeting) in Oslo, Norway in April 2019.

Full information about the methodologies adopted and the results produced is provided in the main WP4 report.

2. Results from the Best Practice Model implementation projects

Best Practice Model 1. Anti-stigma project

Main message

GPs' stereotypes on disclosure are high: anti-stigma training reduces stereotypes and increases GPs' confidence.

Background and rationale

This project aimed to meet the need for continuing education for providers in primary health care to address current misperceptions of NCD and associated negative social representations.

GPs, who play an essential role in NCD detection, diagnosis and follow-up, do not feel confident about making and disclosing an NCD diagnosis and managing properly the associated care follow-up. GPs and their primary-care colleagues can adopt stereotypical views and assign stigma to people with NCDs that are likely to

influence their daily practice and attitudes. These obstacles illustrate the urgent need to provide more adapted and updated medical education to GPs that emphasises the benefits of timely diagnosis and information about available post-diagnosis supports.

Objectives and method

The objectives of the project were to:

- sustain, update and harmonise educational practices across Europe; and
- reinforce positive attitudes towards NCD among GPs and other staff.

WP4 developed an anti-stigma education programme mainly targeting GPs and medical residents. Versions of the programme were introduced to four testing areas among the WP4 European partner countries – one each in Limoges and Lyon (France), one in Lublin (Poland) and one in Sofia (Bulgaria). Implementation leaders of the associated projects in the three countries developed common educational tools, including objectives and contents for the programme, a specific information note for each implementation site, a certificate of participation for attendees and a common data set for data collection and analysis. The impact of the programme was assessed by comparing answers from pre-test and post-test questionnaires after each teaching session in all test site areas.

Eight educational sessions were performed in the implementation sites:

- three identical sessions in Limoges, France;
- one session in Lyon, France;
- two identical sessions in Sofia, Bulgaria; and
- two different sessions in Lublin, Poland – the first a “classical” teaching programme and the second the new anti-stigma teaching programme.

The essential differences between a “classical” and anti-stigma programme are that while a “classical” programme tends to focus on issues such as definitions, epidemiology, aetiology, neuropathology and clinical and scientific diagnosis criteria, anti-stigma programmes focus more on, for example, the patient’s right to know, diagnosis disclosure techniques, personalised care management and care pathways, and tailored support for carers.

The programme was presented in a variety of ways, with differing choice of teaching content, form (plenary sessions versus workshops) and duration (entire day versus half-day) to meet local needs. In total, 291 participants were enrolled in the pilot project across all implementation sites: 181 GPs; 67 medical students; and 43 paramedical practitioners or medical specialists (33 nurses and 10 neurologists). The data set was completed for 223 participants (135 GPs, 57 medical students, 21 nurses and 10 neurologists).

Main results

The main results are drawn from data collected for 192 participants (135 GPs and 57 medical students, at whom the programme primarily was aimed) from the four sites. Plans are in place to analyse the data collected from paramedical staff and neurologists later in 2019.

Attendees and their patients

The mean age of participants (GPs and residents only) was 42.8 ± 13.2 years. A large majority in all sites were female (69% for GPs and 84% for residents). The professional setting was mainly urban (75% GPs and 86% residents). Only 15% had previously trained in geriatrics (8% of GPs and 30% of residents), and 74% had worked with a nurse at the time of the training (71% GPs and 81% residents). The average number of patients living with NCD seen in a week was estimated to be fewer than five for 53% of the attendees (51% GPs and 60% residents).

Basic NCD-related perceived stigma: before training

The pre-test questionnaire aimed to assess the basic level of perceived stigma of the attendees, and focused on four distinct components: emotional, social, courtesy and family stigma. Results were similar across the implementation sites, showing predominance of the emotional and social components of stigma in all sites.

NCD-related stereotypes: after training

Stereotypical attitudes were assessed post-training by clustering results from the questionnaires into five themes: detection and diagnosis processes; diagnosis uncertainty; diagnosis disclosure; post-diagnosis support; and negative representations on NCD and diagnosis.

Results showed significant improvements in Lyon, Sofia and Lublin after the anti-stigma training. In Limoges, the pre- and post-test score difference did not reach significance due to the low number of attendees. Questionnaire responses on detection and diagnosis processes, diagnosis disclosure and negative representations revealed improved perceptions after training in almost all implementation sites. The same trends were observed for the total population (GPs and residents) and for GPs only.

There was a significant effect of age (lower scores in residents than in GPs) related to negative representations on NCD and diagnosis, suggesting that negative representations related to NCD are higher in older practising professionals.

NCD-related confidence post-training

The questionnaire items assessing the attendees' sense of competence were grouped into four themes for the statistical analysis: diagnosis procedure; diagnosis disclosure; treatment/care; and anticipation/risk management.

Across all the implementation sites, total scores significantly improved compared to the pre-training assessments. This was relevant to the total population and to GPs and medical residents separately. The training therefore seems to be effective in improving the sense of competence of attendees.

Satisfaction with the training

Participants recorded "satisfied/very satisfied" regarding the quality of exchanges and discussions during the training (97% in all sites: 91% in Lyon, 96% in Limoges, 100% in Sofia and 100% in Lublin).

Challenges

Several challenges were encountered in implementing the pilot project, including:

- lack of human and financial resources to conduct the project;
- tight time constraints for implementation due to the Joint Action timeframe and difficulty in defining time slots for common work with partners to ensure project coordination and follow-up;
- low participation rates across the sites and difficulties enrolling health-care providers, specifically GPs; and
- difficulties arriving at a consensus on the developed tools and themes for the education programmes and questionnaires among the WP4 partners.

Key messages and next steps

The pilots convey a very positive message, showing that it is possible to improve significantly the sense of competence/confidence of attendees and reduce significantly their entrenched stereotypes regarding NCD. The training was well received by the attendees, and the combination of lectures and workshops appears to be particularly appropriate for such training.

Challenges and barriers related to GPs' availability and motivation to be part of the project. The lack of financial compensation was also a disincentive to participation. Conversely, the main facilitators of the project included added value for clinical practice and patient management and the more engaging format of the training.

Next steps will be to update, sustain and harmonise educational practices across countries through dissemination of the anti-stigma programme on a larger scale in Europe. The target group will be health professionals in primary care and more generally in health-care associations and/or settings, with the aim of reinforcing positive attitudes and practices towards NCD management.

Best Practice Model 2. GP–nurse co-operation project

Main message

GP–nurse co-operation is an efficient option for improving NCD detection and diagnosis.

Background and rationale

Current NCD under-detection and under-diagnosis in primary care is largely attributed to poor NCD management by GPs, coupled with their lack of specific training and limited capacity to identify elements of cognitive decline and use appropriate detection tools. Among the factors that help to explain this finding are:

- stereotypes and stigma that can be encountered in primary care;
- GPs' reluctance to detect and diagnose NCD for fear of misdiagnosis and negative psychological impacts for the concerned patient/family;
- the lack of efficient disease-modifying pharmacological treatments; and
- the absence of personalized care pathways and post-diagnosis support care.

Collaboration with other primary health-care professionals could contribute to overcoming these obstacles. Studies involving advanced practice nurses who have specialised in NCD or have received specific training on assessing cognitive function

with dedicated tools have shown that nurses' skilled interventions can enhance GPs' ability to manage people with NCDs in daily care, provide faster and timely access to specialized care for patients, and help to establish aetiological diagnoses. These studies demonstrate the feasibility of co-operation as a possible means of improving early NCD recognition and detection in primary care by promoting and strengthening collaboration between GPs and nurses.

Objectives and method

The project aimed to improve NCD detection rates in primary care to improve diagnosis quality, reduce delay and improve patient management. The project involved sites in three countries – Bulgaria (Sofia), France (Lyon) and Italy (Rome/Modena).

GPs (88) and nurses (33) working in northern and southern Bulgaria attended preliminary training early in 2018 focusing on the use of detection scales for assessing cognitive, behavioural and autonomy impairment. Two groups – GPs alone (19) and GPs working in collaboration with a nurse (8) – took part in pilot testing related to patient assessment.

France designed a pilot project involving a multidimensional assessment performed by one advanced practice nurse within the Lyon metropolis. The assessment included five scales that were used in common with Bulgaria, one used in common with Italy and some additional tools. The nurse was trained to use the scales by specialists and psychologists. Twelve GPs from the Lyon area agreed to be part of this pilot to assess the effects of collaboration.

The project in Italy was divided into two parts. The first aimed to implement the use of a specific case-finding tool for people with NCD in GPs' daily clinical practice to test its reliability compared to the detection scale currently used in Italy for dementia assessment. The second set out to compare the case-finding tool scores collected separately by a subgroup of Italian GPs and nurses.

The first step for this project was therefore to train the health-care professionals (68 GPs and six nurses) to use the scale through face-to-face and e-learning courses held in March 2018. A second phase involving patients' assessment using the scale was then performed in the Modena Local Health Authority, with 16 patients being assessed, nine of whom were tested separately by GPs and nurses. The pilot project mainly targeted GPs and nurses working primarily in urban settings. Most had no prior experience in NCD detection and diagnosis.

Main results

Subjects

Sixty-two patients (31 in Bulgaria, 16 in Italy and 15 in France) were assessed in the project. The main presenting complaint was cognitive in nature for 55% of the Bulgarian subjects, 88% of Italian and 80% of French. The complaint duration was less than two years for half of the patients assessed across all testing sites and more than two years for the other half.

Only a minority (7% in Bulgaria, 20% in Italy and 33% in France) benefited from external supports. Some were caregiving for another family member at the assesment time (13% in Bulgaria and 20% in France).

Findings

Clinical assessments performed to detect NCD in each implementation site using common assessment scales showed that the assessed patients had good/preserved autonomy for both basic and instrumental daily-life activities, but that cognitive functions were slightly-to-moderately altered in most subjects assessed, suggesting an installed or beginner cognitive decline in almost all subjects.

The multidimensional assessments performed in each implementation site allowed the GPs to formulate diagnosis hypotheses for some patients (Bulgaria and Italy) or allowed nurses to signal proven risks for NCD and/or mood disorders (France). Almost all subjects assessed in Bulgaria were suspected of having a major NCD (74% Alzheimer's disease and 52% vascular dementia, and 7% probable depression). In France, 50% of the subjects tested were considered as at risk for NCD and 8% for mood disorders. Appropriate examinations and management processes were recommended.

Challenges

Challenges across the three pilot projects included:

- an overall lack of human and financial resources in Bulgaria and France; and
- the need for preliminary training for GPs and nurses in Bulgaria and Italy and complex recruitment and involvement of GPs in France, nurses in Italy and GPs and nurses in Bulgaria, presenting major hurdles within the project cycle.

Key messages and next steps

The pilot provides evidence that GP–nurse co-operation is feasible and constitutes an efficient option for improving NCD detection and diagnosis. A collaboration model involving GPs and nurses seems more specifically adapted to population needs and could represent an efficient alternative to detection and assessment in hospital.

The main barriers were insufficient knowledge from primary-care practitioners about NCD, the absence of consensus on detection tools, the potential opposition of the medical profession, and funding and legislation issues related to nurses' activities. The main facilitators were effective solutions for coping with a shortage of GPs, changing demand for care and promotion of high-quality care, growing health costs and the promotion of scientific research in primary care.

On the basis of these results, it is suggested that support be given to:

- training GPs and nurses in cognitive assessment and management;
- legislative and regulatory changes to emphasise and validate advanced practice nursing activity;
- funding nurse interventions in NCD detection and assessment;
- the development of an algorithm for NCD management decisions after detection in primary care, based on agreed detection/assessment tools; and
- the involvement of health-care authorities in such a model.

Best Practice Model 3. Telemedicine pilot project

Main message

NCD detection and diagnosis in nursing homes is feasible and would be supported by telemedicine combined with management of behavioural disorders.

Background and rationale

The third main axis of the WP4 implementation phase aimed to improve NCD detection in specialised care settings, such as nursing homes. Access to diagnosis and associated care for this population is not considered a priority action, as residents are fully supported by the institution in their daily life. Studies nevertheless have shown the added value of detection and diagnosis of NCD for elderly and institutionalised people.

Promoting use of a telemedicine approach in the day-to-day practice of European nursing homes could improve detection and diagnosis rates of NCD and enhance follow-up and post-diagnostic support of residents to increase their quality of life.

Objectives and method

Bulgaria (Sofia), France (Bordeaux) and Greece (Athens) participated in a pilot project that aimed to increase NCD detection and diagnosis rates through telemedicine in nursing homes. The WP4 team leader shared a set of common tools in accordance with the recommendations of the International Consortium for Health Outcomes Management standard set for dementia and a range of project activities was arranged, including a workshop and a systematic literature review.

Main results

The project in Greece involved three nursing homes, Bulgaria one and France two. The nursing homes were in urban settings and had similar average ages of residents, but different percentages of residents with NCD. Staffing was similar in terms of type of health professionals, but different in quantity, largely due to full- or part-time employment.

An assessment of attitudes towards people with dementia found that attitudes were similar among different health-care professionals. In the French care home, however, the attitude was significantly more positive for medical staff than among non-health professionals. The low number of participants did not permit conclusions for Bulgaria and Greece.

The project in Bulgaria demonstrates the feasibility of making an NCD diagnosis in nursing homes through telemedicine. In France, teleconsultation for diagnosis was proposed to nursing home residents and their GPs, but it appears that demand was small. France was the only country where telemedicine was proposed for NCD diagnosis without a preliminary education programme on NCD diagnosis. Greece was able theoretically and pragmatically to educate nursing home staff on NCD diagnosis, including with relevant scales, through telemedicine. The use of telemedicine for patients is the next step. Due to the different approaches, clinical data about residents of each project are not comparable.

Challenges

This implementation project faced several challenges, including:

- lack of human and financial resources;
- coordination difficulties between the WP4 leader and Joint Action partners;
- Bulgaria and Greece putting a major emphasis on staff preparation; and
- the French project struggling to find a medical expert willing to participate.

Key messages and next steps

Lessons learned from the pilot projects show that the challenges are at meso (structural) and macro (health-system) levels, with the setting of the telemedicine device and establishing co-operation, and also at micro (clinical) level, where in the absence of a dedicated education programme (such as in France), NCD diagnosis benefits are not well understood by participants.

WP4 therefore proposes six steps for a successful process. At the meso (structural) and macro (health-system) levels:

1. setting up telemedicine devices in nursing homes; and
2. ensuring co-operation of nursing homes with expert centres.

At the micro (clinical) level:

3. developing an anti-stigma education programme on NCD diagnosis benefits;
4. evaluating residents by nursing home staff;
5. developing resident, family and GP agreements for teleconsultation; and
6. providing teleconsultation facilities.

The following is proposed as a stepped approach to providing teleconsultations for NCD diagnosis:

- install a safe and secure telemedicine device link between the nursing home and the expert centre, involving formal co-operation/contracting between the nursing home and the expert centre;
- develop and deliver an education programme for nursing-home staff, focusing on issues such as an anti-stigma approach and the benefits of diagnosis for residents, which include respecting residents' right to know, supporting them to plan for the future and enabling appropriate diagnosis and care;
- evaluate residents for NCD by nursing-home staff;
- establish agreements between the resident, family and GP for teleconsultations;
- deliver the teleconsultations.

3. Conclusion and key lessons

The core objective of the WP4 implementation phase was to propose concrete ways of addressing the lack of, or delay in, NCD detection and diagnosis in Europe by placing primary care, particularly GPs, at the heart of the process. This reflects primary care's/GPs' central role and immediate proximity to patients in daily practice.

The Best Practice Model projects (10 in total, involving three themes and six countries) accordingly were organized around proposals for:

- specific training that aimed to reduce stereotypical thinking among GPs regarding NCD, while giving them keys to improve their competence and confidence about managing people with NCD (the anti-stigma project);
- a collaboration in primary care through the specific intervention of nurses to assist GPs in NCD detection and diagnosis (GP–nurse co-operation project – Best Practice Model 2); and
- supporting NCD detection and diagnosis for nursing home residents through specific teleconsultations with specialist interventions (telemedicine pilot project – Best Practice Model 3).

The main results are positive and encouraging, clearly demonstrating that it is possible to:

- significantly reduce stereotypical ideas among GPs about NCDs by increasing their feelings of confidence in management through anti-stigma training; and
- improve NCD detection and diagnosis by means of increased collaboration among health professionals in primary care, such as GP surgeries (GP–nurse co-operation) and nursing homes (telemedicine project).

These results therefore provide hope for the development and sustainability of this type of project and action across Europe.

It nonetheless is necessary to recognise that all the pilots faced challenges and difficulties during the operational implementation phase that significantly hindered progress. These included a lack of human and financial resources, difficult coordination with Joint Action partners due to tight schedules, different ethical, cultural, legal, regulatory and administrative approvals and constraints in projects requiring patient data collection, and prior training of involved actors to carry out the project. These issues nevertheless have progressively been bypassed by the commitment, patience and efforts of all committed partners and stakeholders.

WP4 is now preparing a third report, on goals of post-diagnostic support with implementation recommendations for Member States.

Key lessons

The key lessons learned from the WP4 pilot projects aiming to improve NCD diagnosis in primary care in Europe are set out in full in the original report. To summarise:

- GP stereotypes about NCD disclosure are high; anti-stigma training reduces NCD stereotypes and increases GPs' confidence in NCD diagnosis and management;
- GPs/nurses' co-operation is effective in improving NCD detection and diagnosis; and
- NCD detection and diagnosis in nursing homes is feasible and would be supported by telemedicine approaches combined with behavioural disorder management.