



# Effective Long-Term Care underpinned by Data and IT

Roundtable

Malmö, Sweden, 16 June 2023

# Thematic panel discussion: overview

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## Session speakers

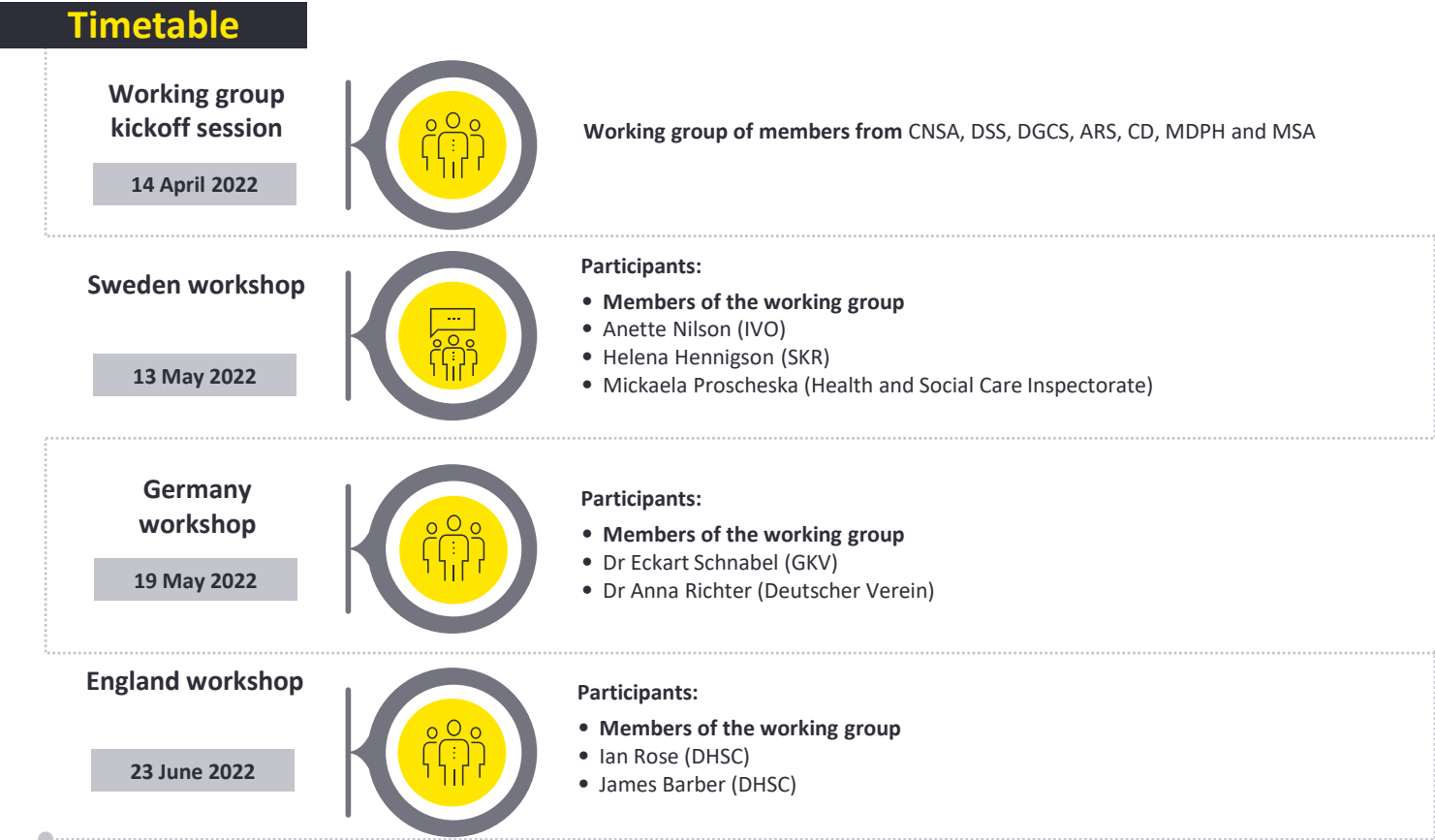
- Emmanuel Gagneux, Vice Président of the National Association of Social Services' Directors, France
- Jordan Holland, Head of Strategy, Adult Social Care Technology and Data, Department of Health and Social Care, UK Government, England
- Irmelind Kirchner, Policy Advisor, Care Policy and Services Section, Health Services Department, AOK-Bundesverband, Germany
- Michaela Prochazka, Coordinator for Elderly Issues and Programme Officer at the National Board of Health and Welfare (Socialstyrelsen), Sweden
- **Moderator**
- Jessica Chamba, Partner, Health and Social Sector and EY Global Deputy Human Services, France



# Introduction to the project

## Objectives of the study

- Analyzing and drawing on beneficial and transposable practices implemented in other countries concerning **relationships with the partners responsible for implementing autonomy policies** at the local level, as well as the **conditions for monitoring and steering decentralized multi-operator policies**.
- Identifying practices that inspire the transformation and functioning of the branch, notably involving issues of the **governance, evaluation** and steering of the policies implemented



# Key learnings from the benchmark (1/2)



**The local level** has been identified as being the best placed to understand the needs and issues of the users in its area, by adapting the guidelines proposed at the national level. In particular, local institutions can best articulate different public policies as a result.



**Local authorities have considerable independence;** they manage the offer and the granting of aid, sometimes via their own financing.



**The national level plays a crucial role in orienting players and standardizing quality.** It acts and reacts to guarantee the principle of equity of access to rights and the overall consistency of the support offer provided by communicating on common guidelines and by actions to monitor the achievement of common objectives (surveys, indicator feedback, inspection visits, etc.).



**Monitoring and evaluation of quality are provided by dedicated independent organizations,** at national level, under the authority of a minister. Their mission is to guarantee maintenance of a satisfactory quality level for the services proposed, both at home and in institutions.



The countries studied place great importance on the use of sound data and **on the implementation of a scientific evaluation approach.** For these countries, this is a means to ensure and guarantee equity between regions.

# Key learnings from the benchmark (2/2)



The rating system for regions and their management of services and institutions attempts to transpose and integrate – as faithfully as possible – **the reality and characteristics of the regions**. Thus it is possible to include the diversity of areas in analyses, and make the comparisons more relevant.



The **indicators** used to monitor and evaluate services are **results-oriented**. They make it possible to measure the impact of support on health and on quality of life.



This strengthened evaluation practice **requires reinforcement of digital data collection and greater interconnection of information systems**. This should facilitate more frequent information transfers, enabling real-time exploitation of data to enhance steering and decision-making. **The three countries studied have made evaluation data a priority issue for the next few years.**



The countries studied make **measurement of the satisfaction of users and their families** central to the evaluation process.



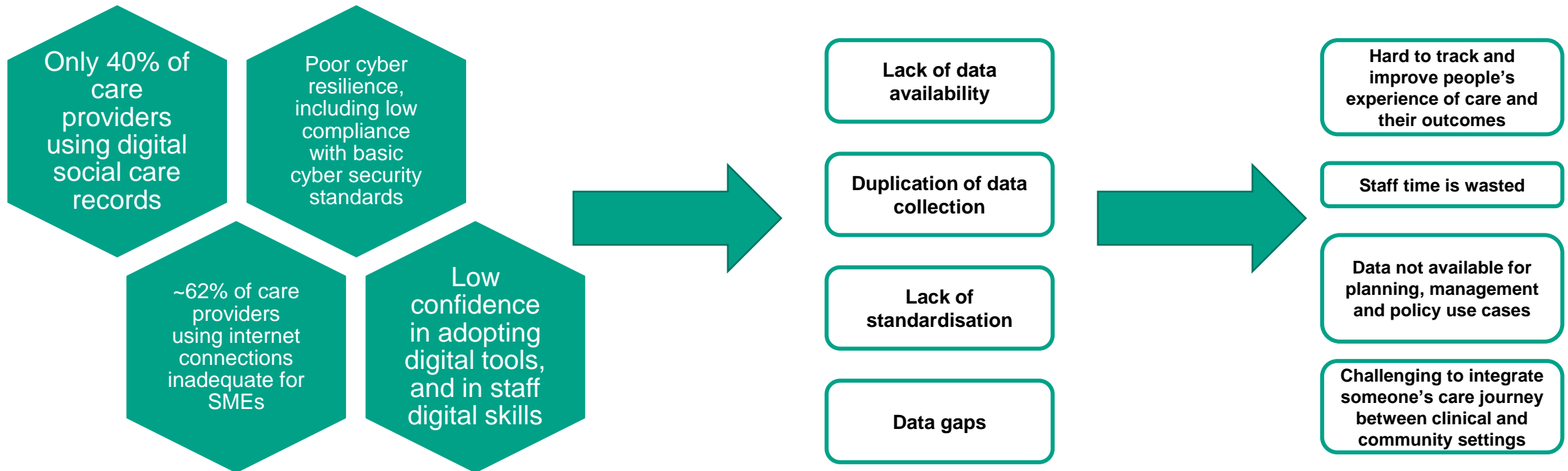
Lastly, the three countries studied **cultivate transparency in the results** and in the analyses that complete evaluations, in the spirit of open government. Data is communicated to the public, which is useful both for users and for all players in autonomy policy, who can also depend on it.

# Where are we now? Digitisation and data in adult social care in England

Adult social care in England is delivered by about 18,000 organisations, with the vast majority being independent sector (private) providers. These organisations deliver care in about 40,000 sites, employing about 1.5m people.

Compared with England's National Health Service (NHS) adult social care providers lag behind in their levels of digitisation. This, in turn, impacts on the quality and availability of data about social care.

## Starting point in England, c.2020/21



# Where are we now? Digitisation and data in adult social care in England

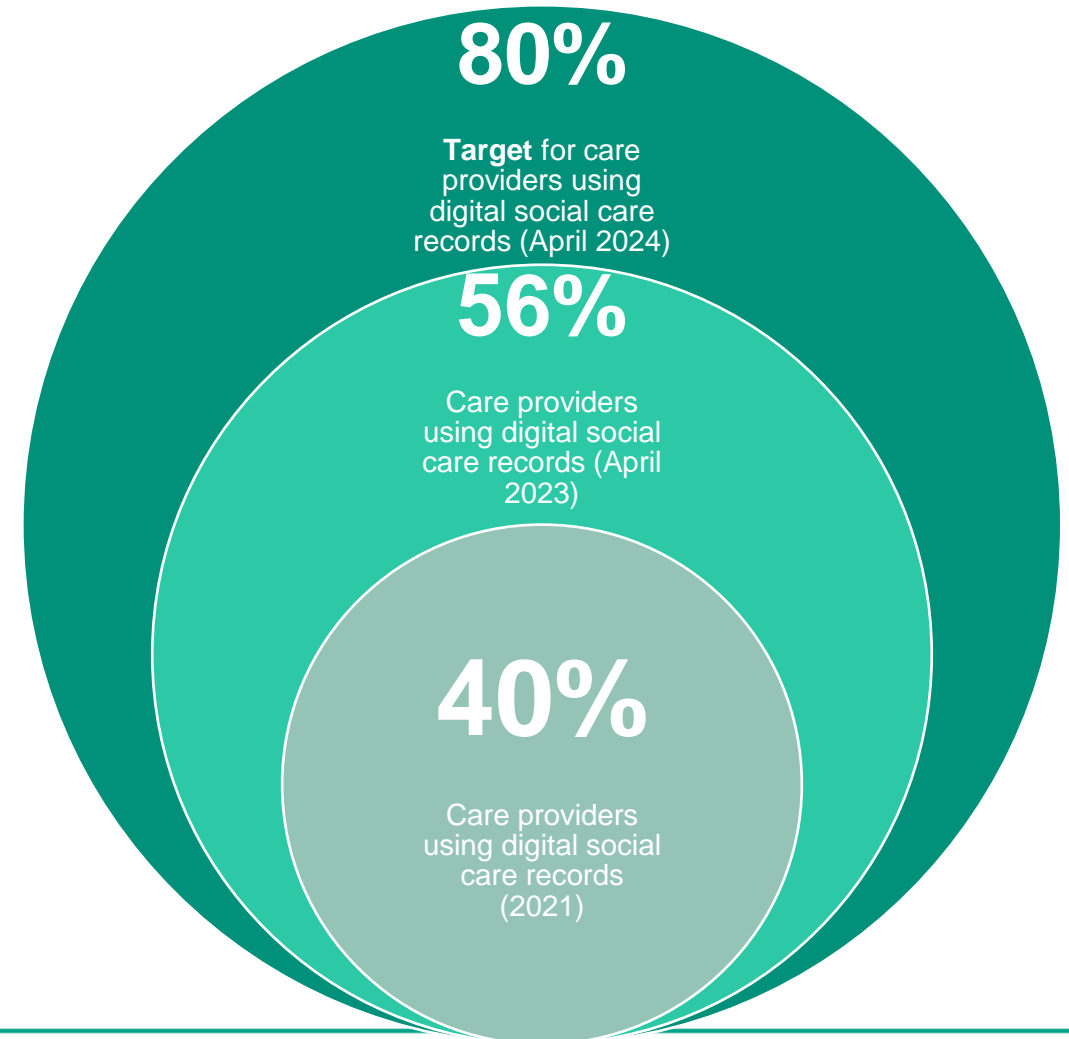
In 2021, the UK Government committed to invest at least £150m to digitise the adult social care sector, plus up to £50m to improve data collection, as part of a raft of measures designed to reform social care provision.

## Digitisation

- Improve adoption of digital social care records (DSCRs) from 40% to 80% by March 2024
- Drive adoption of proven care technologies
- Improve the digital skills, connectivity and cyber resilience of care providers

## Data

- Streamline and improve data collection
- Establish new data collections and bridge data gaps
- Improve access to data and produce better insights from this data



# Open comparisons National, Regional and Local Sweden

**Michaela Prochazka**, onc RN, MPH, PhD

Programme Officer, Coordinator for elderly affairs



# The open comparisons in elderly care contains 4 different parts

- Registries – mandatory and non-mandatory
- Survey to the municipalities
- Survey to the units who provides elderly care
- Survey to those who use elderly care

# The survey to the elderly care units

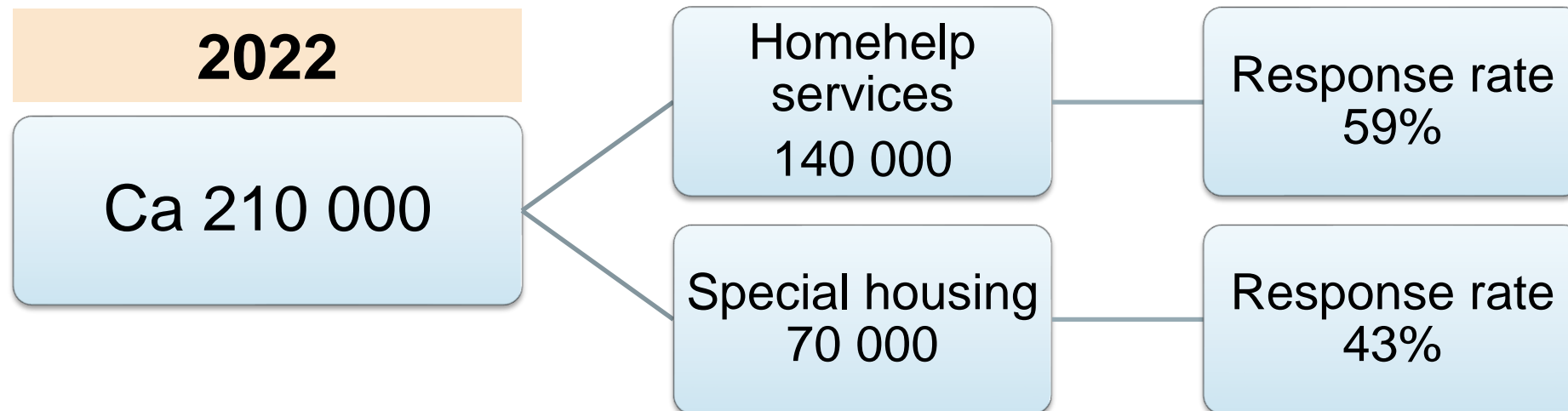
- Annually since 2007
- Response rate around 85 percent
- Engages 290 municipalities and about 5 000 special housing and home care units
- Topics that cannot be found in other sources of data
- Both public and private (profit/not for profit)

# Example of topics

- If the unit have a routine for staff to discover if the elderly persons has been subjected to violence or abuse by a relative
- Proportion of elderly persons (at the unit) with a plan that contains information about their wishes and needs in connection with the meal
- If the staff speak other languages than Swedish

# Survey to older persons

- $\geq 65$  years with homehelp services or living in special housing
- From 2013 yearly to all ( except 2021)
- Results presented as:
  - Excel to be used by persons in leading position
  - Written report to the government



# The Elderly Guide

- to provide overall information and a possibility of comparing municipalities and units of special housing.

*To obtain in-depth information about services and care, one is recommended to contact the municipality or unit in question.*

The image shows a screenshot of the Äldreguiden website, which is a service from Socialstyrelsen. The website is designed to help users find and compare elderly care services. The main navigation bar includes links for 'Jämför äldreomsorg', 'Så ansöker du', and 'Mer om äldreomsorg'. The header also features the logo 'Äldreguiden - EN TJÄNST FRÅN SOCIALSTYRELSEN' and a search bar labeled 'Sök Äldreguiden'. The main content area is titled 'Hitta & jämför äldreomsorg' and includes a section for 'Börja med att välja vilken typ av äldreomsorg vill du jämföra.' with radio buttons for 'Hemtjänst' (selected) and 'Boende'. Below this, there is a link to 'Läs mer om hemtjänst, boenden och andra insatser i äldreomsorgen [här](#)'. The 'Välj kommun' section has a dropdown menu with 'Alingsås' selected. The 'Välj inriktning' and 'Välj regiform' sections have dropdown menus with 'Inriktning (Alla visas)' and 'Regiform (Alla visas)' selected respectively. At the bottom, it states 'Du har gjort följande val: Hemtjänst, Alingsås' and '10 träffar hittades'. A final note mentions that if you need support in your daily life, you can apply for home care services, which include service interventions and personal care.

Äldreguiden  
- EN TJÄNST FRÅN SOCIALSTYRELSEN

Jämför äldreomsorg   Så ansöker du   Mer om äldreomsorg

Start > Jämför äldreomsorg

## Hitta & jämför äldreomsorg

Börja med att välja vilken typ av äldreomsorg vill du jämföra.

☒ Hemtjänst   ☐ Boende

Läs mer om hemtjänst, boenden och andra insatser i äldreomsorgen [här](#)

Välj kommun

Alingsås

Välj inriktning ⓘ   Välj regiform ⓘ

Inriktning (Alla visas)   Regiform (Alla visas)

Du har gjort följande val: Hemtjänst, Alingsås

10 träffar hittades

Om du behöver stöd i din vardag kan du ansöka om att få hemtjänst. Det finns två inriktningar inom hemtjänsten: serviceinsatser och personlig omvårdnad.

Äldreguiden  
- EN TJÄNST FRÅN SOCIALSTYRELSEN

Jämför äldreomsorg   Så ansöker du   Mer om äldreomsorg   Om Äldreguiden

Här kan du jämföra äldreomsorg i din kommun >

Äldreguiden vänder sig till dig som ska söka äldreomsorg till dig själv eller en närstående. Här får du information om äldreboenden och hemtjänster i hela Sverige.

Så ansöker du om äldreomsorg >

Här beskriver vi hur det går till att söka äldreomsorg. Det kan finnas skillnader beroende på vilken kommun du bor i.

Dina rättigheter >

Behov av stöd i vardagen kan handla om hemtjänst, äldreboende eller annat stöd. Här kan du läsa mer om dina rättigheter.

Vad kostar det? >

Här kan du läsa om vilka avgifter du får betala om du har hemtjänst eller bor på äldreboende.

Socialstyrelsen

# Effective Long-Term Care underpinned by Data and IT Germany: Quality Assurance visible for all

New indicators and publication framework

# Four elements of quality management

**The legal framework for a comprehensive quality assurance system of LTC connects four elements:**

- 1. Internal Quality Assurance System** is a task for each care provider
- 2. External quality evaluation** conducted by independent inspection organisations (person-centred, sample)
- 3. Dialogue on quality** between inspectors and providers as part of advisory character/learning system
- 4. Publishing data on quality** as consumer-oriented information



# Internal quality management: quality indicators

## Quality indicators area 1: Maintenance and support of autonomy

1. Maintain and support mobility
2. Maintain/support autonomy with regard to everyday routine tasks (self-care)
3. Maintain autonomy concerning day-to-day activities

## Quality indicators area 2: Protection against factors that are detrimental to health

4. Incidence of pressure sores
5. Falls with wide-ranging health consequences
6. Unintentional weight loss

## Quality indicators area 3: Support for individual needs

7. Conducting integration conversations (after moving to the facility)
8. Use of restraints
9. Use of bed side panels
10. Up-to-date pain assessment

Data on these indicators  
are transferred to a  
neutral collection point  
(twice a year)

Plausibility check  
Reports sent to: providers,  
regional associations of  
the care insurers, external  
inspection bodies

## External quality inspections: quality indicators

- Once every year (announced)
- Results of internal quality management (report) is taken as basis
- Aspects relating to professional care management within the facility such as management of risk factors and hygiene management are taken into consideration
- Important: dialogue on quality, advice for improvement through external inspectors

In addition, each inspection looks at a sample of up to nine care home residents, evaluating the quality of care for each individual. Inspection focuses on aspects of care closely aligned to the individual care grade assessment (*decides the care grade for each individual with care needs: six areas covering mobility, communication and cognitive abilities, daily life competence, ability to cope with and manage burdens related to illness, organising daily life and participation in social life*).

The results of these person-centred care inspections fall into four categories:




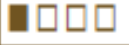

- a) No deficiencies or particular points of concern
- b) Points of concern without risks or negative outcomes for resident
- c) Deficiencies which carry a risk of negative outcomes for resident
- d) Deficiencies resulting in negative outcome for resident

# Publication of results online for each provider

Results for Internal quality indicators are published for the 10 indicators in 5 grades:

Results quality well above average:	●●●●●
Results quality slightly above average:	●●●●○
Results quality near average:	●●●○○
Results quality slightly below average:	●●○○○
Results quality well below average:	●○○○○

External inspection results are published for different aspects of individual care; 4 grades:

	No or slight quality deficiencies
	Moderate quality deficiencies
	Significant quality deficiencies
	Severe quality deficiencies
	Not applicable for residents included in sample

Best results achieved by providers:	
Worst results achieved by providers:	

Results will be comparable across providers.  
No overall scores but detailed information – differentiation from previous system.

# Thank you.

**Irmelind Kirchner**

Referentin Pflege  
Abteilung Pflege  
AOK-Bundesverband

+ 49 30 34646 2662  
[Irmelind.kirchner@bv.aok.de](mailto:Irmelind.kirchner@bv.aok.de)  
[www.aok-bv.de](http://www.aok-bv.de)

# Thematic panel discussion Long-term care undepinned by data and IT

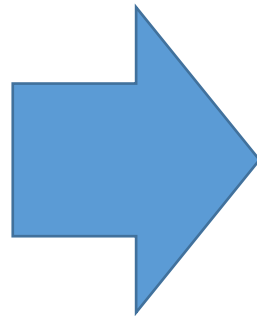
The building up of data policy in France

**MALMÖ – JUNE 16 2023**

2000-2014



Each administration  
decides to develop its  
own system or to buy  
it on the market (100  
county councils, 100  
strategies)

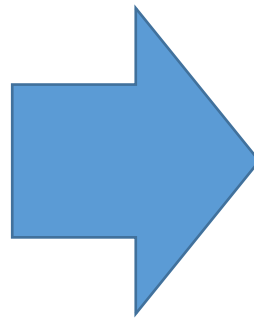


No data policy  
No common definitions  
No communication between systems  
« Manual » data collection reported to  
the central administration

# 2014-2020 : convergence



**Counties councils are  
gradually obliged to  
use labeled  
softwares**

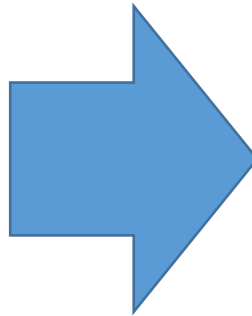


**Common definitions  
Automatic collection of data  
by central administrations  
Impact on work organization  
Implementation issues**

# 2014-2020 : unification

**Counties are obliged to use a unique « in-house » system**

**Building block approach  
(first block 80 M€)**



**Common definitions**

**Automatic collection of data  
by central administrations**

**Limited cost for local  
authorities**

**Risk of failure**

**Reduction of local decision-  
making powers**

**Assesment of work  
organization impact**

# Conclusion

**What are we still missing ?**

**Were other strategies possible ?**

**Pairing with other  
databases (e.g health,  
school, employment data,  
care providers systems)**

**Governance**

**Legal clearance**

**Labelisation**

**Data exchange standards  
API**

## Where we are

Limited digitisation

Lack of data availability

Duplication of data collection

Lack of standardisation

Data gaps

## How we will get there



Building our understanding of the data we all need through engagement and our online survey

Working through local health and care commissioners to embed change in their area

Building capacity within local authorities and care providers to deliver digitisation in their own organisations

Using commercial levers to proactively shape the technology supplier market to achieve our vision for improved care outcomes

## Where we want to be

*National projects to get us there, guided by our 10 principles*

### Streamlined and improved existing data collections

Client level data collected from local authorities

Provider level data collection and national minimum dataset

Fit for purpose ASC survey and Survey of Adult Carers

New data collections only to bridge data gaps, including for workforce and unpaid carers

### Improved access to the data and better insights

New national digital product to improve access to social care data

Strengthened Adult Social Care Outcomes Framework metrics

### Sector digitisation

Improve adoption of digital social care records, 80% by March '24

Deliver a comprehensive learning offer to improve staff digital skills

Improve the cyber resilience of care providers, inc. use of secure email

Support providers to improve their connectivity, including for mobile care

Drive adoption of care technologies that support independence

Improve the confidence and capability of buyers, inc. market management



# Annex | 10 principles for moving forward and transforming adult social care data in England

1. **Data will be collected once and made available to those who need it**, to avoid national and local government collecting the same data separately from care providers, unpaid carers and those who access care and support

2. **Data will routinely be shared back with data suppliers wherever possible**, in an accessible manner appropriate to the needs of different data users for additional insights and benchmarking purposes

3. The **option for automated data collection methods as an alternative to manual collection will be available wherever possible**, to minimise the data collection burdens on data suppliers

4. **Frequency of data collection will be the minimum needed** to meet data needs

5. **Data collections will be based on data already held by a data supplier, wherever possible**, and where new or amended data is required, it will be kept to a minimum

6. **Feedback will be sought from relevant stakeholders wherever possible**, prior to finalising the details of new or amending existing collections

7. **The collection of very granular data will be kept to a minimum** where such data is not held in digital format and therefore would present a significant burden on providers to submit manually. If individual level data is being collected, **providers will not be expected to bear the burden of anonymising or pseudo-anonymising such data**, rather this will be considered when identifying an appropriate data collection mechanism

8. **Information will be processed and made available safely and securely**, and only processed in accordance with the legal framework, including data protection legislation, with respect for people's privacy and with due regard to their consent. Reasons for providing access to data will be transparent, open, and understood

9. **Access to data for research and analysis will be made available through SDEs**, which will ensure that the highest standards of security, privacy and transparency are upheld

10. **Changes to new and existing data collections will be reviewed and approved by the relevant governance structures**, to ensure changes are appropriate and proportionate

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