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*Dem@entoring*



*Dem@entoring*



## **DEM@ENTORING**

**Live and learn – Innovative  
ICT based learning and  
mentoring approaches for  
Alzheimer's communities**

**ERASMUS+ KA2 (2018)**

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### **The Mentoring Relationship Cycle Intellectual Output 4 (IO4)**



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## Introduction

Dementia diseases increasingly challenges people and societies across the world, due to the risks of social isolation, economic challenges, and impact on family life.

However, this challenge is not just felt and borne by the people with dementia, but also by their friends and families. People with dementia need extra care – and their carers call for more development of knowledge and attention about the challenge before them, about dementia, but also personally in the role as carer.

Being a carer can be a professional choice – often involving training on practical and mental issues and theoretical understandings, that one would face as a professional career. But informal carers are often left with little or no formal training to rely on – and a huge emotional challenge by their direct relation in addition to the challenge of simply being able to maintain a somewhat normal life also.

The Dem@enting project tries to support these informal carers in three ways – by learning about dementia itself, by learning how to manage the role of being an informal carer and by learning about how to share these experiences with other informal carers.

## The Dem@enting tool

The Dem@enting tool is an online platform that offers an education and training program. The aim of the program is to provide carers with specific knowledge and skills and to create and train dementia carers as e-mentors to provide mentoring to other carers in the set of peer support groups. The Mentors will be trained on how to deal with the practical and psychological burden of dementia. This training program will focus on carers' needs providing all the necessary information about dementia symptoms, progression and available treatments, specific skills enabling them to effectively cope with issues related to



dementia, training in the management of the physical, psychological and financial burden of dementia.

In addition, Mentors will be trained in mentoring skills to provide their knowledge and experience to other carers – mentees – through the online platform. By joining a dementia support group, Mentees will have the chance to meet and get to know others who are going through the same experiences. They will have the opportunity to discuss topics that are relevant to their situation. They will learn more about dementia and how to cope with caring and finally, they will be part of a peer support group (network) with people sharing common experiences.

An adult learning and education approach have been applied, addressing health and wellbeing to enhance an understanding of dementia for these informal carers and allow them to efficiently cope with the dementia symptoms, jointly raise awareness, and decrease stigmatization. The e- mentoring training program is being implemented in different EU-countries.

## What does this guide do?

The Mentoring Relationship Cycle is a guide on how to use the Dem@enting tool in your organisation. The model takes you through a series of steps that can improve your planning, uptake, and impact of activities, initiatives, and reporting.

The overall aim is not only to create an impact but also to have a circular approach, to reuse and include experiences within your organisation. By applying these steps, continued development across the community of stakeholders and users can be enhanced.

Following the steps, you will have designed a strategy, the necessary templates and tools to



be used, created the basis of the necessary cooperation and networking structures, but also a list or database of collaborators and trainers to cooperate with.

## The Mentoring Relationship Cycle

The Dem@enting tool empowers participants and enables the formation of groups and mentors. The mentors and mentees then enable a wider dialogue with the community which allows new participants/carers into the course and then has the ability to expand the learning and content of the course (videos, statements, ideas etc).

But once one such cycle is set in motion, the mentors can/would be a path to initiate new sets of courses – via networks, friends, relations, organizations – that would create new cycles. The same might apply for the mentees – while not mentors, their positive participation can inspire other informal carers to join – just as the groups obviously have an impact on the wider community, they are part of.

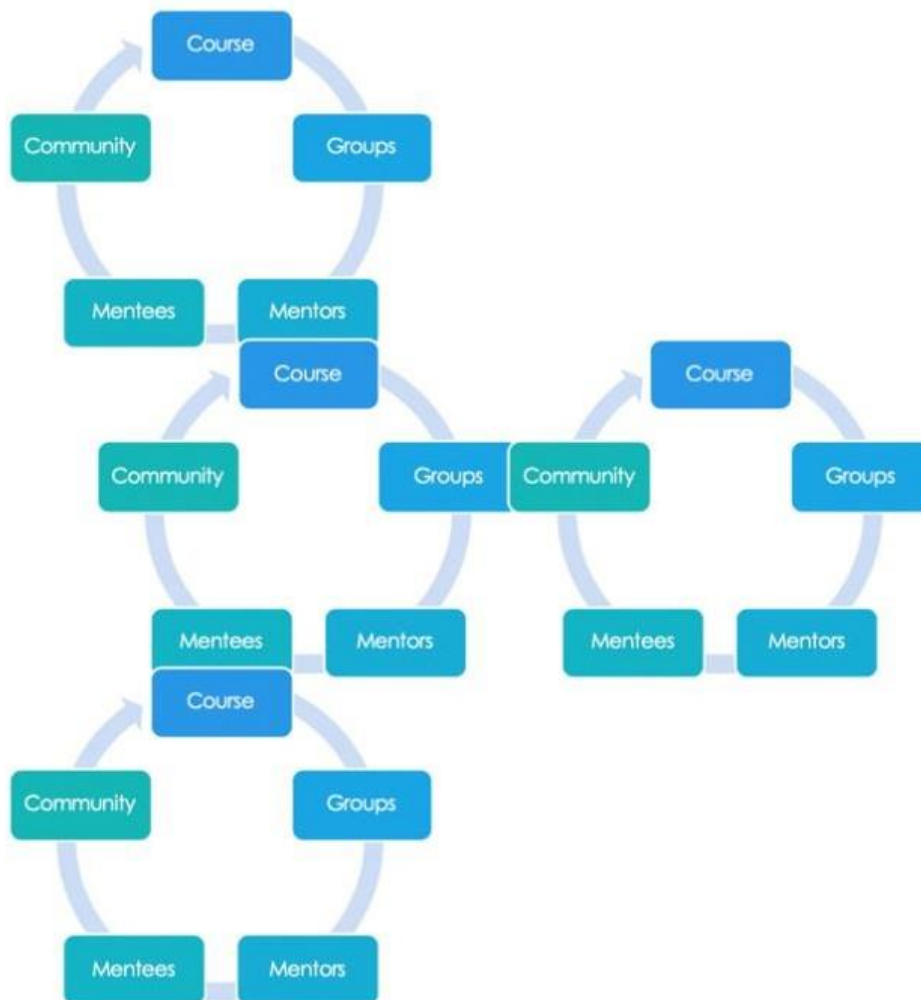
Obviously, one should not expect this to always be self-sustained – but it shows the value and strength of initiating community-based groups. The combination of a targeted effort of a local, regional, or national organization working long term to nudge new groups into the course will have ripple effects.



## How do you start

It is vital to understand, that this is an iterative process. User participation in the courses builds groups, and groups develop mentors that are necessary for the creation of mentor-mentee relationships to build and empower communities to create new courses.

This also means that patience and learning is both needed and possible - you will not need to do both at once or indeed be able to - the regenerative process takes time to evolve.





The following sections will describe the steps of this relationship cycle.

## Who are your users?

The Dem@enting program will greatly support the effort of people with dementia and their families and carers by helping them improve their daily life. However, before using the tool you should consider more specifically who your users are.

### *Criteria for selection*

Based on your existing experience, build a set of criteria (check list design) to both focus and clarify potential and existing initiatives. How would you like to reach your target group? From where? etc. Ensure your team members and stakeholders are involved in giving input for to this.

### *Needs analysis*

To expand understanding and verify your user group needs, ensure you involve several users in a Needs analysis (report form). This can be done by interviews and surveys, but open-ended questions must be used. Of course, users are all unique, but interviewing a sample of potential users will both improve your result and help you fine tune criteria for selection.

### *Skills gap identification (mapping)*

How do your users vary? Do they have complementing skill sets? Are some groups struggling with a similar set of challenges?

## How to create groups?

There are a few things you need to consider before creating the groups to participate in the program.



### *Size, composition, frequency, mode*

Your needs analysis defines a series of choices regarding the types, sizes, and number of groups that you can support. Think also about digital formats – or how digital formats might supplement physical meetings, if your users have the digital literacy to do so.

### *Support and repetition*

These groups are social connections – though connected by common challenges, real connections take time and repetition to build. Make sure to involve users more than once, make sure you support their participation with information, active dialogues, solving practical issues etc.

### *Challenges and opportunities (mapping)*

What problems do your users report? What hinders their participation (if so)? What opportunities/resources to they reveal – both might help reassess the selection criteria.

### *Design of group meeting template*

Prior to all activities a group meeting template would be helpful for both organizers and participants. This helps clarify specific needs for the meeting to ensure successful outcomes. In Annex B you will find a list of information points.

## What is a mentor?

A mentor is defined as a source of wisdom, teaching, and support, and is not a person who observes and advises on specific actions or behavioural changes in daily work. Mentoring consists of a long-term relationship focused on supporting the growth and development of the mentee, the one who is trained. The difference between a mentor and a coach is that coaching involves a relationship of finite duration, with focus on strengthening or eliminating





specific behaviours, here and now. Coaches help professional's correct behaviours that detract from their performance or strengthen those that support stronger performance around a given set of activities (The Merriam-Webster Online Dictionary). E-mentors support the growth and development of others, in this case families and formal caregivers to people with dementia, and thus the people with dementia themselves, through an on-line service centre.

### *Personal skills*

We encourage the implementers/developers to also use the Dem@entoring tool to learn more about mentoring as a skill set – and how to identify these in your groups.

### *Availability*

Given the nature of your audience and the types of informal carers, a key component is also availability. Having time to spare is obviously a challenge, but without both skills and availability, mentoring is not possible. Ensure both the group, the mentor, and the mentees that expectations about time and frequency are discussed.

### *Match*

Identification can take many forms. Some might be useful as matches due to past work experience, heritage, hobbies – be open to several possible matching opportunities. Often matching a mentor with a number of mentees will help clarify these possibilities.

### **What is a mentee?**

A mentee is defined as the person who is being advised and trained by the mentor.



### *Personal skills*

Being a mentee is also a very active and open role. To grow and evolve as a mentee, you must also be willing to consider new actions, perceptions, ideas, and advice. Some might grow from mentee to mentor. Some might not.

### *Availability*

Having time to interact with the mentor is central. But also, availability to reflect and possibly adapt practices to respond to suggestions. The mentee does not have to change – but should be open to it.

### *Match*

Neither mentor nor mentees are “right”. Needs and personalities are different. And anything from timing, tone, stress, and more might make a useful match of a multi-step process.

## What is a community?

Obviously, a community is a collection of people tied together by geography and/or interests. But it is also a result of choices.

### *Local, regional, national*

Local communities can sometimes be defined by housing – national or international by passion. Regardless, remembering to use and integrate the relevant mentor/mentee/professional communities are a key component to expanding the relationship cycle.

### *Private – professional*

Informal carers are not professionals. But they are dedicated experts of their lives and challenges with the potential to inspire and involve others. Be open for opportunities to involve both types of communities.



### *Expanding*

The goal is not to grow, but to support. Expanding can be a tool – as well as strengthening social connections.

## Uptake & dissemination

### Systems

The Dem@entoring tool is designed to be used across multiple languages as a MOOC – a Massive Open Online Course – which allows a very large number of users access to a joint platform. This provides opportunities for joint experiences and languages, but also a flexible tool for national, regional, or local decision makers for integration and as supplement for other existing initiatives.

Research done as part of the Dem@entoring project has shown a strong potential across EU Member States for a tool that allows informal carers to better learn, share, and leverage experiences that they have already gained. But the ability to both gain a wider understanding of the challenges they face and a community to connect with is a unique addition to many existing initiatives.

### Local environments

The supportive environments in the different countries are diverse. Some are organized by public authorities at state or local level, some by patient organizations, and some by carer/citizens organizations.

This can sometimes lead to a strong local culture and commitment to help both people with dementia and their carers, but more often leaves the strongest focus on the people with dementia and little or no focus on challenges and experiences of the carers. And, as a result, this can at times further aggravate the position of these carers, that end up dealing with both care,



loneliness, lack of knowledge and support, and a limited set of tools to handle everyday situations.

## Target groups

The tool can be used by different organizations - e.g. Alzheimer Associations, Dementia Day Care Centers, or Memory Clinics - to improve the carers' understanding of challenging situations they might later be in, for national or local authorities as a way of establishing better network and cohesion with carer organizations or groups or as a supplement to existing public information initiatives.

The tool allows a dual role – the sharing of information and experiences, but also the empowerment of a group of carers willing to act as mentors for other carers. For mentors and mentees this slightly transforms the situation they are in from an often lonely or bewildering situation, to a joint experience where both challenges and good tips can enhance the overall situation for all.

## Implementation

The training program can be used to both educate, train and empower informal carers that could otherwise struggle to find targeted information for their situation and challenges. It can also be used to connect and expand the community of informal carers, that would previously be dealing with isolation in addition to other challenges. These two approaches should ideally be combined in the implementation of the Dem@entoring course as a tool to empower informal carers – more learning about dementia and coping strategies breeds activity, more activity breeds more learning about dementia and coping strategies.

Experiences from other self-management initiatives show, that there's an enormous will, power, and essentially resilience in people. People are essentially self-caring and self-managing



24 hours a day, discovering ways to cope and adapt to changing situations, but with scarce or little professional knowledge about the challenges before them, the solutions they find can be very challenging to discover or less than ideal to use. This means that a group activity with professional support greatly enhances their existing experiences and efforts – respecting the fact that they still need to self-care and self-manage the remaining part of their life, so these solutions have to be practical, identifiable, and directly applicable.

But before actually initiating Mentoring Relationship Cycles, here are a number of key advices for a successful implementation.

## Good practices on implementation

### *Invite the community*

It is vital for the implementation for any tool, that one finds practical applications and allow a local user experience to grow. This means reaching out to national, regional or local stakeholders to organize first step seminars, workshops, conferences or similar, where even just a few initial users

– mentors or not – are given the opportunity to share both their experiences as carers, but also their experiences with the tool.

With the outbreak of COVID-19 being declared a pandemic by the World Health Organisation, people worldwide are facing a major challenge. COVID-19 has significantly affected all our lives, but it is also challenging our ability to adapt and be resilient.

Major world events are often an inflection point for rapid innovation – a clear example is the rise of e-education, cancelling all in-person classes, because of the COVID-19. The COVID-19 pandemic has changed education forever. As a result, education has changed dramatically, with the distinctive rise of e-learning, whereby teaching is undertaken remotely and on digital



platforms. Research suggests that online learning has been shown to increase retention of information, and take less time, meaning the changes COVID-19 have caused might be here to stay.

This provides a very important first step of finding initial ambassadors or at least cases for later communication and uptake.

### *Show – don't tell*

New tools are notorious by being, well, new. This means implementation is a break from existing patterns and cultures, that initially – obviously – has little knowledge of the benefits of a new system. So, it's a good idea to be practical. Instead of talking about the tool, show the tool. Arrange perhaps a few laptops to allow participants to start exploring.

### *Involve users*

The Dem@entoring project involved people with dementia and carers in the development process. Yet it is also a good idea to involve users in the implementation phase also. Ask their advice, use their network to extend your own, integrate their comments in actual communication

– these are your most valuable ambassadors as these obviously are the future users.

### *Be patient – and supportive*

Any new initiative takes time. So, initiating courses and enabling groups might peter out for all kinds of reasons. Be patient and initiative new attempts at various stages of the year and in various kinds of citizens groups or institutions.

The groups and the mentor-mentee relationships can grow very strong over a number of years, but can also often require support in initiating/coordinating meeting, having an



available venue/digital service, having access to/help to create a public webpage with updates about their activities or events, a contact person to help guide initial meetings or communication, or similar – always remembering that these support activities can and should be done with or by the group; not for them as the empowerment and ownership of the group hinges on a significant part of self-efficacy.

### *Develop an info-kit*

Gathering input about the different elements of the Dem@enting tool will allow the organiser to create a Frequently Asked Question section either online or in a folder always available for any participant or future workshop organiser.

Following the preparation of the meetings, the organizer needs to collect all evaluation and data –

we recommend using this to prepare a short summary report that will a) provide valuable input for the organizer and the community, b) provide information on how the meeting results can feed into existing practices, c) record additional challenges that might have been identified during the meeting, d) record any issue or difficulty acknowledged by the participants during the meeting. As mentioned, the group meeting should be repeated for at least 2-4 times.

The info-kit will contain both information in a report form but also template forms for others to use. An online info-kit is easily accessible by anyone and can be downloaded and used with slight moderation by other departments.

### *More on implementation?*

Several project and initiatives have tried to map and research the value and elements to a good implementation. We can recommend further learning to be found from these two Horizon 2020 research projects:



On interventions within chronic conditions:

*COMPAR-EU*

<https://self-management.eu/>

On interventions involving e-health solutions:

*ImpleMentAll*

<https://www.implementall.eu/9-outcomes-and-resources.html>





## Testimonials

It is highly recommended that local organizers of the Dem@entoring training program create testimonials from former participants. Testimonials are written or recorded statements and recommendations from satisfied participants and it is one of the most powerful ways to promote the program to other potential mentors or mentees.

Contacting former participants of the program by email is the easiest and quickest method of collecting testimonials. If possible, you can also create video testimonials, which create more attention and trigger more emotions. However, the most important is that the testimonials are truthful and point out what is good about the program. Once you have collected your testimonials you can use them on your website, on printed materials, or on your different social media channels.

The Dem@entoring platform will also include testimonials from people with dementia, their caregivers and from different stakeholders. The testimonials will focus on the barriers faced, on which solutions are found through the program, and on the impact and long-term benefits.

## Evaluation tools

Evaluation is a process that critically examines a program. It is necessary to ensure or improve the effectiveness and sustainability of the program, which makes it an important part of the project management for a successful implementation.

After implementing the Dem@entoring tool, it is a good idea to periodically assess and adapt the different elements of the tool to ensure it is as effective as it can be. Evaluation can help you identify areas for improvement and help you realize your overall objectives for using the tool more efficiently.



Another important reason for evaluating your use of the Dem@entoring tool is that it enables you to demonstrate the program's success or progress. The information you collect allows you to better communicate your program's impact to others, which is good for public relations, the possibility of recruiting both mentors and mentees, and retaining support from local stakeholders.

Evaluation involves collecting and analysing information about the program's activities, characteristics, and outcomes. After you determine your approach to the evaluation and your overall objectives, you will need to choose your evaluation tools. Evaluation tools can be both qualitative and quantitative and we recommend you use mixed-methods approach using both interviews and a survey.

In Annex C you find a template for a survey that can be send to all participants of the Dem@entoring program. The survey can be adjusted to fit the local context and questions can be added or removed. We advise you use an online survey tool to distribute the survey. This will make it easier to collect data and generate statistics.

### *Links*

For further reading on evaluation and assessment; we recommend the tools below, but also stress that these are for professional use – as a volunteer mentor, you should of course care about the content and output of your great efforts, but as a private citizen, conducting professional evaluation processes are:

Center for Clinical and Translational Science Mentor Evaluation  
Form: <https://ictr.wisc.edu/mentoring/mentor-evaluation-form-examples/>

The Mentoring Competency Assessment:



<https://ictr.wisc.edu/mentoring/mentor-evaluation-form-examples/>



## Annex A: Tips from across Europe

In addition to the Dem@entoring tool, these individual tools for might also help you:

### Greece

Panhellenic Federation of Alzheimer's Disease and Related Disorders

[www.alzheimer-federation.gr](http://www.alzheimer-federation.gr)

Athens Alzheimer Association

[www.alzheimerathens.gr](http://www.alzheimerathens.gr)

### Poland

Polish Alzheimer Association

Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimerera

[www.alzheimer-waw.pl](http://www.alzheimer-waw.pl)

(ŁTA) Łódzkie Towarzystwo

Alzheimerowskie <http://www.alzheimer-lodz.pl>

(NCN) Narodowe Centrum Nauki; JPND Network (Neurodegenerative Disease Research) <https://www.ncn.gov.pl/wspolpraca-zagraniczna/wspolpraca-wielostronna/konkurs-jpnd>

Ministerstwo Zdrowia

<https://www.gov.pl/web/zdrowie/demencja>



## Italy

Alzheimer's Association Italy

<http://www.alzheimer.it>

[http://www.alzheimer-  
aima.it/](http://www.alzheimer-<br/>aima.it/)

Caregiver Familiare

<http://www.caregiverfamiliare.it/>

Alzheimer Uniti Onlus

[www.alzheimeruniti.it](http://www.alzheimeruniti.it)

Care4Dem Project

<https://care4dem.eu/moodle30/>

eLILY Project

<https://elily.eu/>

Apps4Carers

Project

<http://www.appsforcarers.eu/about-the-project/>

## Sweden

Sweden Alzheimer Association

Alzheimer Sverige

<https://www.alzheimersverige.se>



## Denmark

Nationalt Videnscenter for Demens

<http://www.videnscenterfordemens.dk>

/

Alzheimerforeningen

<https://www.alzheimer.dk/>

Sundhedsstyrelsen

<https://www.sst.dk/da/viden/demens/anbefalinger-og-haandboeger/haandboeger>

## International

Alzheimer's Associaton

<https://www.alz.org/help-support/caregiving>

CaregiverPro <https://caregiversprommd-project.eu/>

Alzheimer Europe

[www.alzheimer-europe.org](http://www.alzheimer-europe.org)

## Related policies

Preliminary list (to be expanded/explained)

## CHRODIS

+AHA

E-health

Inclusion

Integrated

careEquity





## Annex B: Tools for planning group meetings

### Group meeting template

A group meeting template should consider the information points below. The list is non-exhaustive:

- Title of meetings / tone of messaging
- Dates, frequency and duration of meetings
- How this corresponds with the target group and profile information
- Number of people to participate and moderator information
- Aim of activity (e.g. first, second, third meeting – clear mentor-mentee relationships, undecidedmentor-mentee)
- Information and questions for participants
- Notes for mentor/moderator/organizer
- Infrastructure (technical/physical) needed for meeting organisation
- Evaluation information needed – and collection process (number of people participated, assessment, etc.)

### Organization of the actual meeting

With the above template in mind, other practical issues still needs to be addressed. This involves:

- Agenda (topics + timeline) for the workshop with speakers, moderators and workshop leadernames
- Location of workshop information – updating information on company’s social media or other channels to attract participants.
- Handout for meeting and material for moderator/organizer (participants, needs analysis)
- Handout materials for participants e.g. information about venue, organizer,



stakeholders, community etc.

- Assessment template with questions for the participants.

This is important to consider as this can help you determine gaps in communication with the set target groups or gaps in dealing with the meeting itself.

- Signature list for the participants? If needed for documentation
- Impact evaluation form for the organizer? Distributed how (paper, digital, immediately after – day after etc.)





## Annex C: Draft of questions in evaluation survey

(This is a draft of questions the survey can contain)

### Part 1 – Background questions

- 1.1: Gender?
- 1.2: Age?
- 1.3: What municipality do you live in?
- 1.4: Years of education?
- 1.5: What kind of dementia does the person you take care of have?
- 1.6: How are you related to the person that has dementia?
- 1.7: Why did you enroll for the online program?
- 1.8: Where did you hear about the program?  
(online, media, friends, trusted institutions, other – which?)

### Part 2 – The content of the program

Rate the statements below on a scale from 1 to 5 (*using Likert scales for each of them*).

- 2.1: I trust the information and directions that I have been given during the program
- 2.2: The content of the program has been communicated in an educational and understandable way
- 2.3: It has been worth the time and effort to attend the program
- 2.4: I will tell others that the program is good
- 2.5: The content of the program was relevant for my situation

### Part 3 – The mentor

Rate the statements below on a scale from 1 to 5 (*using Likert scales for each of them*).



- 3.1: The mentor was skilled and well prepared during the sessions?
- 3.2: It was good that the mentor himself knows about being a carer of person with dementia?
- 3.3: It was easy to communicate and have a dialogue with my mentor
- 3.4: It was easy to communicate and have a dialogue with my fellow mentees

#### **Part 4 – overall evaluation**

- 4.1: The technical components worked as expected during the program
- 4.2: Was the program as you expected based on the information you had been given by the coordinator before the start of the program?
- 4.3: How satisfied have you been with the program overall?



## Annex D: Mentoring assessment

The Mentoring Competency Assessment (MCA) is a validated tool designed by the University of Wisconsin-Madison.

### Mentoring Competency Assessment (MCA)Mentor MCA for Self-Reflection

#### Mentoring Skills

Please rate how skilled you feel you are in each of the following areas: [Think about your skill generally, with all your mentees. Please only choose 'not applicable' (NA) when a skill cannot be applied to any of your mentees.]

Not at all skilled

Moderately skilled

Extremely skilled

**1**

**2**

**3**

**4 5**

**6**

**7**

**N/A**

1. Active listening

2. Providing constructive feedback

3. Establishing a relationship based on trust

4. Identifying and accommodating different communication styles

5. Employing strategies to improve communication with mentees



6. Coordinating effectively with your mentees' other mentors
7. Working with mentees to set clear expectations of the mentoring relationship
8. Aligning your expectations with your mentees'
9. Considering how personal and professional differences may impact expectations
10. Working with mentees to set research goals
11. Helping mentees develop strategies to meet goals
12. Accurately estimating your mentees' level of scientific knowledge
13. Accurately estimating your mentees' ability to conduct research
14. Employing strategies to enhance your mentees' knowledge and abilities
15. Motivating your mentees
16. Building mentees' confidence
17. Stimulating your mentees' creativity
18. Acknowledging your mentees' professional contributions
19. Negotiating a path to professional independence with your mentees



20. Taking into account the biases and prejudices you bring to the mentor/mentee relationship
21. Working effectively with mentees whose personal background is different from your own (age, race, gender, class, region, culture, religion, family composition etc.)
22. Helping your mentees network effectively
23. Helping your mentees set career goals
24. Helping your mentees balance work with their personal life
25. Understanding your impact as a role model
26. Helping your mentees acquire resources (e.g. grants, etc.)

We thank you for your time spent taking this survey.



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**Mentoring Competency Assessment (MCA) Mentee MCA for Self-reflection**

**Mentoring Skills**

Please rate how skilled you feel your mentor is in each of the following areas: [We understand that you can only speak from your personal experience. Please try to rate a skill whenever possible, reserving the 'not observed' category for cases where you have no basis for assessment].

Not at all skilled

Moderately skilled

Extremely skilled

**1**

**2**

**3**

**4 5**

**6**

**7**

**N/A**

1. Active listening

2. Providing you constructive feedback

3. Establishing a relationship based on trust with you

4. Identifying and accommodating different communication styles

5. Employing strategies to improve communication with you

6. Coordinating effectively with other mentors with whom you work

7. Working with you to set clear expectations of the mentoring relationship



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8. Motivating you
9. Building your confidence
10. Stimulating your creativity
11. Acknowledging your professional contributions
12. Negotiating a path to professional independence with you
13. Taking into account the biases and prejudices s/he brings to your mentor/mentee relationship
14. Working effectively with mentees whose personal background is different from his/her own (age, race, gender, class, region, culture, religion, family composition etc.)
15. Helping you network effectively
16. Helping you set career goals
17. Helping you balance work with your personal life
18. Understanding his/her impact as a role model for you
19. Helping you acquire resources (e.g. grants, etc.)

We thank you for your time spent taking this survey.