

Celebrating 10 years of the European Working Group of People with Dementia, 2012–2022



Acknowledgement

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“We are seen as people first. Our diagnosis does not define or label who we are and all Alzheimer Europe staff and their members treat us as equals.”

Chris Roberts, current Chairperson of the European Working Group of People with Dementia (EWGPWD)

“Over the last decade, we have become beacons of hope for the many people with dementia, not just in Europe but throughout the world.”

Helen Rochford-Brennan, Chairperson of the EWGPWD from 2016 to 2020

“The major achievement, in my mind, was our very active participation in the recognition of dementia as a disability. We helped write history in this field!”

Helga Rohra, Chairperson of the EWGPWD from 2012 to 2016

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Welcome

Congratulations to the European Working Group of People with Dementia (EWGPWD) on its 10th anniversary! The group was launched by Alzheimer Europe and its member associations in 2012 and is composed entirely of people with dementia, who are nominated by their national Alzheimer associations. Each term of office lasts two years, with the current term ending in October 2022. The group operates independently and members elect their own Chairperson and Vice-Chairs. The Chairperson is an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights.

Group members work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people living with dementia. They also consult on EU-funded research projects and participate actively in Alzheimer Europe's annual conferences and contribute towards Alzheimer Europe's work on ethical issues. They attend international dementia-related events, including at the European Parliament, as representatives of the EWGPWD.

Until the end of 2021, the important work of the group was funded by an operating grant under the European Union's Health Programme. It is now funded by a new operating grant from the European Union, under the Citizens, Equality, Rights and Values (CERV) programme.

The Alzheimer Europe team and Board look forward to continuing their collaboration with the EWGPWD and would like to express their gratitude to the Executive and members of the group, past and present, for their hard work and support.



Meeting to discuss the setting up of the EWGPWD, Glasgow, Scotland, 2012



Most recent meeting of the group, Luxembourg, 2022

Executive members of European Working Group of People with Dementia reflect on 10-year anniversary

Alzheimer Europe interviewed the three Chairpersons that the European Working Group of People with Dementia (EWGPWD) has had since it began, to get their thoughts about this 10-year anniversary, about their time as Chair and about the work of the group. The two current Vice-Chairpersons also commented on their reasons for joining, their priorities, and why working groups like the EWGPWD and national dementia working groups are important.



Chris Roberts

Chris Roberts, Chairperson from 2020 – present

This year marks a decade since the European Working Group of People with Dementia (EWGPWD) first met, in 2012. What are your thoughts on this anniversary?

I am very honoured and thrilled to be the current Chair for this important anniversary. Alzheimer Europe was one of the first organisations to help provide an independent voice to people with dementia. Since then, many other countries have also set up similar groups. We need to continue with this work and involve more people from many other countries and backgrounds as experts by experience in their own working groups.

We, as a group, show that there is life after a diagnosis and we try to inspire others to 'come out', to stand up and be counted, to speak and to change the lives of others, especially for those that do not communicate any more. This collaboration really works and needs to be replicated across other patient groups to utilise their expertise. This, in turn, means they provide peer support for each other, which is invaluable.

All this happens because we are enabled and not disabled. We are seen as people first. Our diagnosis does not define or label who we

are and all Alzheimer Europe staff and their members treat us as equals.

You served as Vice-Chairperson from 2016 to 2020 before becoming Chairperson of the group in 2020. Could you share one or two personal highlights from your time in the group so far?

I served as a Vice-Chair from 2016–2020, then became the Chairperson near the end of 2020, until the present. I have enjoyed being part of the group, contributing to their work, making life-long friends and acquaintances. A couple of personal highlights for myself were:

Being supported and asked to make a statement at the 4th European Parliament of Persons with Disabilities, on 6 December 2017 in Brussels. My statement was made on behalf of and for people living with dementia.

“We are seen as people first. Our diagnosis does not define or label who we are and all Alzheimer Europe staff and their members treat us as equals.”

The second highlight I have in mind was the honour to be one of the co-authors of a peer-reviewed article about Public Involvement in dementia research, “Our reflections of Patient and Public Involvement in research as members of the European Working Group of People with Dementia”, published in the journal “Dementia” in 2020.

These are only a couple of things that being in the group has helped me to achieve; things that I would never have imagined were possible for me to do.

As Chairperson of the group, you have a place on the Board of Alzheimer Europe. What does it mean to you to hold this position and do you feel it helps the work of the group and of Alzheimer Europe?

Having a place on the Board of Alzheimer Europe is an honour and a display of trust that is very important to me. To be involved in the Board on equal terms with the other members of the Alzheimer Europe Board shows that our involvement in the organisation is meaningful and not just to “tick the box”; that our contribution is appreciated and wanted. It also helps the group to understand the workings and finances of Alzheimer

Europe, and shows them the support from Board members, that goes into the continuation of our group.

The group was originally formed to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia and more recently, to contribute towards research projects in the context of Public Involvement. Do you think these goals are being achieved?

I personally think this has absolutely been achieved and we look forward to the group continuing to achieve these important goals, to constantly evolve, adapt and learn, so that our successes can be built upon.

The group is involved in several projects in which Alzheimer Europe is a partner. We are informed about the projects and we are able to provide our perspectives about several issues relevant to these research projects. This helps to ensure that the topic that is addressed is relevant to people with dementia. We also help to ensure that the way the research is conducted is appropriate and respectful to the participants who are living with dementia.

Additionally, it is very nice that we have been involved in supporting early-stage researchers (ESRs), as this helps them to gain an understanding, right from the beginning of their career, of the relevance and importance of involving people with dementia in research, and how to go about this. It not only increases understanding, but helps enable ESRs to adapt and revise their project where new learning has taken place. Patient engagement can save money and time, as well as bringing valuable insight and advice that you can only receive from someone living with the experience of a life-changing condition.

Overall, we feel, as a group, that the experience is very positive and mutually beneficial for all involved. Our thanks to everyone who has helped us to make this possible and successful. This involvement not only helps the

researchers, but helps us as well. It gives us confidence, focus and brings meaning, but mainly gives us all hope; hope that there will be a future for others like ourselves.

What are some of the main obstacles encountered in the important work the group does?

One of the main obstacles we encounter during our work with others is that, sometimes, researchers do not know how to approach people with dementia. They may feel scared, may not have the skills or may not have met a person with dementia before. Many assumptions can be made, often wrongly and maybe sometimes rightly. Many people we start to work with are simply not aware that people with dementia can be consulted through Public Involvement, etc. This is sometimes linked to the stereotypes they have about dementia, which are actually of people in more advanced stages of dementia.

We do need support and understanding, but it is also important that activities are carefully planned and are adapted to our needs. Our involvement should never be tokenistic.

Language can be and is a huge barrier, and not just the languages of our different group members, because our meetings are held in English, but we also need to use a common language in our meetings about research, not to use acronyms for example, to help make these meetings accessible for everyone.

“We continually strive to find ways to enable everyone to contribute to the group’s work through our appropriate practices, support and adaptation.”

All of this can make it difficult for some EWGPWD members, as well as professionals, to participate, but we continually strive to find

ways to enable everyone to contribute to the group’s work through our appropriate practices, support and adaptation.

What do you think has been the EWGPWD’s biggest achievement so far and what do you hope it can achieve in the future?

I think one of the group’s biggest achievements so far, and one of which I am very proud, is how it has adapted to the difficulties faced during the COVID-19 pandemic. The pandemic changed everything for everyone. Face-to-face meetings completely stopped. Many members had never participated in online meetings before and some were not confident with the technology that was needed to do so. Working online is not for everyone, but can be especially problematic for people with cognitive difficulties.

“One of the group’s biggest achievements so far, and one of which I am very proud, is how it has adapted to the difficulties faced during the COVID-19 pandemic.”

Despite these difficulties, we managed to keep going, we adapted to the new ways of working and carried on with our important Public Involvement activities, with our contributions to various European projects, with our advocacy work and European-level research. All of this has given us great satisfaction and pride!

The Alzheimer Europe team worked very hard to support us during those difficult and trying times. We must not forget, either, the very important support we received from our families, our friends and our supporters, as well as from our national Alzheimer’s associations, who assisted us to carry on with this work. All of this support helped make it possible for the group to continue its work during such trying times and we are very grateful.

Helen Rochford-Brennan, Chairperson from 2016–2020

What are your thoughts on this anniversary?

As we celebrate this momentous milestone it's a time to look back with joy and gratitude at all that has been accomplished.

To the original Trail Blazers: You were fearless go-getters and our heartfelt thanks to you and your families and also to the Alzheimer Europe team for the support and encouragement in setting up the group. It was privileged to join you after two years, you had been well established and, together, we set the scene for the rest of the decade. There have been ups and downs, sadness and goodbyes but it's been an incredible journey.

Through the most difficult times for many of us in the group we have been fortunate to have the empathy and unwavering support from Ana and Dianne from the Alzheimer Europe team. Over the last decade, we have become beacons of hope for the many people with dementia, not just in Europe but throughout the world.

On behalf of the group, I want to thank the Alzheimer Europe Board, researchers, funders, the European Commission, European Parliament, the World Health Organization, the Alzheimer Europe team and so many others who gave us the opportunity to participate in Public Involvement. We could not have done it without you! Today we've become a successful group and thanks to your help we are recognised internationally for our work.

“Over the last decade, we have become beacons of hope for the many people with dementia, not just in Europe but throughout the world.”

To the members of the European Working Group, past or present: You should be so proud of yourselves for not giving up along the way, you stayed the course as long as possible, you've coped with all the changes, language barriers, traveling to different countries, different hotels, the pandemic. You embraced technology. Your passion and excellence are

unmatched. Your skills and knowledge have impacted on the lives of so many throughout Europe and beyond. I have no doubt the next decade will reach new heights beyond my wildest imagination. Happy 10th anniversary and thank you, Alzheimer Europe for your foresight in helping set up this group. We shall forever be grateful.

You joined the European Working Group of People with Dementia (EWGPWD) in 2014. What were your reasons for joining and what were your expectations? Were these expectations met?

I joined the group because I believed it was an opportunity to influence policy at a European level. I saw a real opportunity to change policy through the parliament and my professional background advocating for the rights of people with disabilities gave me the confidence to join the group. I wanted to work to make the lives of people living with dementia and their families better and in particular to be a voice for people living in rural areas. There are many spokes on the wheel of life but first we're here to explore new opportunities and that's why I was so driven to join a group I felt could make real change.

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I expected the EWGPWD to be serious and solemn. I was very apprehensive about language and wondered how this would work! I wasn't expecting the strong voices of advocacy that I encountered, and at my first meeting I saw their need for change was like mine! I definitely was not expecting the sense of fun and camaraderie either. This experience has been one of the privileges of my life.

Once I saw that Alzheimer Europe was willing to listen and take on board the views of the EWGPWD, I knew we could influence real change. We did not just talk, our conversations led to action.



Helen Rochford-Brennan

You served as Vice-Chairperson from 2014 to 2016 and then became Chairperson of the group in 2016. You have stayed on as a member of the group after stepping down from your position as Chair in 2020. What did it mean to you to hold those positions and could you share one or two personal highlights from the past eight years?

There have been many achievements and highlights over the years. On a personal level receiving the Mano Amiga award was a wonderful moment, as was attending the European Parliament. Seeing MEPs listen and engage with people living with dementia was very special. Standing beside three MEPs from my home country and knowing their commitment to the cause gave me great hope. Being invited to European Parliament Disability Forum and watching my colleague Chris Roberts speak at that event made me very hopeful for the future.

But the real highlight has been watching my colleagues in the EWGPWD build their capacity, grow in confidence and influence change in their own countries. I feel very proud to be part of this group of change makers.

“The real highlight has been watching my colleagues in the EWGPWD build their capacity, grow in confidence and influence change in their own countries. I feel very proud to be part of this group of change makers.”

What do you think has been the EWGPWD's biggest achievement so far and what do you hope it can achieve in the future?

The EWGPWD is now an important stakeholder in the European dementia landscape and this is an important and critical achievement in the human rights of people with dementia.

I believe that the EWGPWD, supported by Alzheimer Europe, has been part of a Europe-wide shift in the mind-set of researchers. Now, funding requires researchers to include the voice of people living with dementia; they are now co-creators and robust partners. I think the leadership shown by members of the EWGPWD will influence research and policy for years to come.

The group was originally formed to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia, and more recently, to contribute towards research projects in the context of Public Involvement. Do you think these goals are being achieved?

Yes, I do. I believe the engagement has been meaningful and not tokenistic. Alzheimer Europe has approached this work in a very ethical manner. It was a great honour to sit on the Board of Alzheimer Europe and I believe this is an important example of shared power and how the voice of people with dementia can influence at the highest level.

Of course it is a work in progress, and there is more work ahead – that's a reminder for my colleagues coming after me: No slacking! The achievements of these recent years have been considerable.

What are some of the main obstacles encountered in the important work the group does?

The main obstacle has been the language barrier. More people from many different countries could participate if there was funding for interpreters. We must be careful, going forward, that we are finding and listening to the voice of the person with dementia and not their support person, if there is a language difficulty.

Helga Rohra, Chairperson from 2012–2016

What are your thoughts on this anniversary?

My first thought on this anniversary is, what courageous and tough people diagnosed with a form of dementia we are! We stand up and speak for ourselves. The members of the EWGPWD were among the first in Europe to raise awareness about the challenges of living with dementia at young age, and the first to do so at a European level.

Alzheimer Europe was the first organisation, worldwide, to support and include people with dementia (*via* this group) in different projects, highlighting important aspects of living with dementia at the social, research and political levels.

Our work was fundamental during these 10 years, to support the start of national dementia strategies. We can be very proud to be included in research projects in our own countries and even in political decisions referring to aspects of living with dementia.

We, the former and current members of the EWGPWD, are the real heroes with dementia, who, despite our diagnoses, are strong dementia campaigners. We lecture at universities, some of us are authors with our own published books, we are speakers at dementia conferences, we help in guiding projects,

and we are showing the world there can still be a good life with dementia.

“We, the former and current members of the EWGPWD, are the real heroes with dementia, who, despite our diagnoses, are strong dementia campaigners.”

I congratulate all of us and our support organisation, Alzheimer Europe, with all its members. For the next 10 years, I wish for new pathways in which people with dementia can continue representing their peers, at high-level health and political functions.

You were a founding member of the European Working Group of People with Dementia (EWGPWD), which was formed in October 2012 and met for the first time at the 22nd Alzheimer Europe Conference. What were your reasons for joining and what were your expectations? Were these expectations met?

Let me go back to the year 2011. I can remember the Alzheimer Europe Conference in Warsaw (Poland), at which I was invited as a speaker. Together with my colleagues from Scotland and Poland we were a kind of



Helga Rohra

“I congratulate all of us and our support organisation, Alzheimer Europe, with all its members.”

highlight: people with dementia at younger age (we were in our fifties at that time). The interaction with many other participants gave me confidence in our still existing abilities. At a previous Board meeting, I had already emphasised the need for people with dementia to be more involved, a point on which Jean Georges, Executive Director of Alzheimer Europe was in agreement. Alzheimer Europe

was keen to involve people with dementia more in its activities (e.g. in working groups and at conferences) and we took the opportunity to share ideas on how to involve people with dementia more fully in the organisation, including on the Board. That was the point when the EWGPWD was born! A historic moment in the dementia movement!

In spring 2012, a group of people with dementia together with staff from their national Alzheimer organisations met in Glasgow to learn how a working group can function. Scotland, with its Scottish Working Group, had already some experience and were the first in Europe. What an honour to meet and learn from my friends there!

Later in 2012, the EWGPWD was founded as an Advisory Group of Alzheimer Europe. I strongly believe that the very beginning should never be forgotten as well as the first people with dementia involved. My personal motivation to join was the chance to work, to get involved at a European level, to learn from other Alzheimer organisations. The main reason was my wish to show the world that people with dementia are still valuable and to change the perception on dementia: “See us, not only our disease!” I was convinced that as part of a group and with the support of Alzheimer Europe we can do very valuable work in this respect.

My expectations – after six years work in the group – were more than met and I feel very honoured and happy to have been a part of amazing projects.

What did it mean to you to be the group’s first Chairperson, and could you share some things that were/have been important to you, both in your role as Chair and as a member of the group?

To become the group’s first Chairperson meant a lot to me. Like in ordinary life, this means responsibility, a need for a good command of the English language, good insights in dementia-related topics, a tough way to represent our voice at meetings.

The very sensitive difference I always felt was the balance between feelings! The members

still have abilities and are passionate to contribute in projects, BUT they are fragile and tears or sadness are a part of this as well as very personal issues. I had one aim: to make everyone feel valued and feel comfortable in the group! And I know I did a good job!

I myself experienced an enormous uplift by being a Chair. I was grateful that I could carry on a part of my former life, before my diagnosis. Alzheimer Europe and the EWGPWD became a kind of family. Dementia remains a key part of my life, a positive topic – a start of a new, a different life. I started to write books to encourage people with dementia to LIVE, to get active in their own associations.

What would be one or two personal highlights from your two terms in this position (2012–2014 and 2014–2016)?

The EWGPWD and our achievements are simply unique! In 2012 and even some years after, very few patient organisations had patients who spoke for themselves.

We were invited as keynote speakers or partners in workshops with professionals. A highlight was our involvement as co-researchers, and being partners in many projects like INDUCT or ROADMAP – to name just a few. Our contribution in writing papers, even books about ethical aspects or rights of people with dementia was also very important.

What do you think has been the EWGPWD’s biggest achievement so far and what do you hope it can achieve in the future?

The major achievement, in my mind, was our very active participation in the recognition of dementia as a disability. We helped write history in this field! Our pioneering work will be honoured by the coming generations!

“The major achievement, in my mind, was our very active participation in the recognition of dementia as a disability. We helped write history in this field!”

I strongly believe that the members of the EWGPWD can achieve changes in their own countries, can be active partners in dementia strategies. I am very confident that the European Working Group will join in global projects, since we are the experts!

The group was originally formed to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia. In your view, are these goals being achieved?

The activities of Alzheimer Europe definitely reflect our views and focus on our priorities. I’d like to point out that the staff of Alzheimer Europe not only gives us the professional but also the sometimes needed moral support! The projects are discussed and evaluated. I always felt like a partner in a team! I have deep appreciation for this attitude! I think each member feels highly valued in his or her advisory function and there lies the uniqueness of Alzheimer Europe and our EWGPWD. We are examples to be followed by other patient organisations!

What are some of the main obstacles encountered in the important work the group does?

Some of the main obstacles are sadly our own national organisations that we represent. I noticed in all these years that some support their members, such as Wales, Ireland and Scotland – to name some of them. By “support” I mean: showing interest in the activities we carry out, giving us the opportunity to talk, to activate people in our own countries, to include us in projects. The political sector, especially the social and health sector could be influenced in a very positive way by giving people with dementia “power” to represent themselves.

Honestly, I tell you, I feel sad that my friends in the group are not honoured in all the countries. We are all heroes – we are all working for a better dementia world! I am also confident that working groups of people with dementia will and have to exist in every country! I also have a dream: A person with dementia as a Member of the European Parliament!

Comment from Kevin Quaid, current Vice-Chairperson

I joined the EWGPWD because it gives me a chance to represent my country on a European stage and to give a voice to people with dementia, but especially to give people with Lewy body dementia (LBD) a voice, because I still think that the scale of people who actually have LBD is so underestimated and I want to change that.

My priorities are quite simple: I want the rights of people listened to and understood, and to make sure nothing happens or no decision is made about us unless we are included in both the question and the answer. More needs to be done to find a cure for dementia, and more needs to be done to ensure that people who have dementia are given a proper diagnosis. The stigma needs to be, once and for all, completely taken out of the equation when talking about dementia.

“Working groups are of vital importance in each and every country and it is of even more importance that we have our European working group, to look at how different countries deal with dementia.”

Kevin Quaid

Working groups are of vital importance in each and every country and it is of even more importance that we have our European working group, to look at how different countries deal with dementia and the different advancements that each country makes. These can then be shared. One glaring



Kevin Quaid

example is how some countries can offer DaTscan and other countries don't. This is a brain scan which can identify whether a person has LBD or not.

Comment from Bernd Heise, current Vice-Chairperson

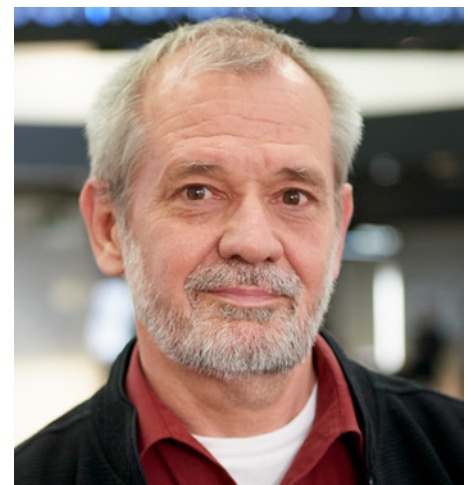
There are many reasons for my commitment to people with dementia: I first encountered dementia about 20 years ago, in the company where I worked. I met an employee who had significant memory problems. He had to leave the company within a few weeks. Before that experience, I didn't even know that dementia could affect younger people also. Now, I have dementia myself in the early stages and would like to stand up for people who are in a similar situation to me.

Before I joined the EWGPWD, I learned a lot about dementia at the Alzheimer's association in Munich and I later became a member of the advisory group of the Deutsche Alzheimer Gesellschaft (German Alzheimer's association). There, I was asked whether I would like to support the EWGPWD, which I gladly accepted.

I see my task in the EWGPWD as giving people with dementia a voice, and ensuring that various areas of help and support are developed. There is an urgent need to educate people about the problems and concerns of people with dementia.

I hope to be able to pass on my knowledge and experience regarding Alzheimer's, in the group and beyond. I also see a specific task for myself: to push technical supports for people with dementia, because of my professional background and my great interest in this topic. My goal is that these technical supports will enable people with dementia to live independently, for longer. The University of Munich and the Munich Alzheimer's association have started a project to create technical systems for people with dementia, based on an assistive voice computer.

As a person who has always been in contact with other people and has stood up for others, I am convinced that exchanging ideas with one another and thinking outside our borders is very, very important in order to develop new ideas. I see a chance to do just that, in the EWGPWD. We have the opportunity to bring together national strategies for people with dementia, to listen to and learn from each other. In the EWGPWD, I see the chance to actively do something for people across Europe who have dementia.



Bernd Heise

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Bernd Heise

Alzheimer Europe Chairperson Iva Holmerová and Executive Director Jean Georges share their perspective on the group and its work

In this interview, Chairperson Iva Holmerová and Executive Director Jean Georges look back at some of the key achievements of the European Working Group of People with Dementia (EWGPWD) over the past 10 years, at how the group was formed and how it has evolved over time.

This year marks 10 years of the European Working Group of People with Dementia (EWGPWD) – what are your thoughts on this anniversary?

Iva Holmerová: As the Chair of Alzheimer Europe, I am truly proud about the fantastic progress that Alzheimer Europe has made in giving a voice to people with dementia in all our activities, including on the Alzheimer Europe Board. I have always enjoyed the collaboration with Helga Rohra, Helen Rochford-Brennan and Chris Roberts, the

“Our organisation was a true pioneer in this field, as there were only limited experiences of such groups of people with dementia from our national member organisations.”

Jean Georges

chairpersons of our European Working Group of People with Dementia, who participated in our Board meetings and made sure we become a more inclusive organisation.

Jean Georges: When we set up the European Working Group of People with Dementia in 2012, our organisation was a true pioneer in this field, as there were only limited experiences of such groups of people with

dementia from our national member organisations. Since, we have seen the development of national working groups of people with dementia in a number of European countries and, like Iva, I am really proud of the impact that the group has had on our own work, but also that of our member organisations.

The group’s role has evolved significantly since its beginnings in 2012. Can you tell us more about how the group started and how it has changed?

Jean Georges: When we decided to set up the group in 2012, the focus of the group was more inward looking, as we wanted to make sure that we had mechanisms in place to include the views and experiences of people with dementia in our work and that we had a group that could advise us on how to make the association more inclusive and how to discuss dementia or portray people living with dementia. Since these beginnings, the group has become more and more active in our advocacy initiatives at a European level and they have contributed to consultations of the World Health Organization and met with Members of the European Parliament and national health ministers.

Iva Holmerová: The European Working Group has also been an active contributor to a whole range of EU-funded research projects where Alzheimer Europe was asked to lead the Public Involvement activities to ensure that the research aims, methodology, activities and results reflect the views of people



Iva Holmerová



Jean Georges

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Iva Holmerová

with dementia. Recently, the group has even engaged with small and medium sized enterprises (SMEs) or pharmaceutical companies to provide input on the development of mobile apps for people with dementia or the planning of clinical trials.

How does membership of the group work and are there any challenges faced when composing a new group, every two years?

Jean Georges: The members of the group are nominated by our national member organisations and the group is comprised of between 10 and 15 members. At the beginning, it proved more difficult to identify sufficient members to join the group and we had to primarily rely on people nominated by English speaking organisations.

Iva Holmerová: Thankfully, this has changed and we now have a much broader representation from more European countries. We may have to see though how we can encourage the participation of people with dementia from minority ethnic groups. Also, the last group had a much higher number of men than women and we should definitely see how we can have a better gender balance for the upcoming work.

Regarding the carers and supporters of the people in the group, how important is the role that they play?

Iva Holmerová: The group would not be able to function without the fantastic support provided by the carers and supporters who accompany the people with dementia who are members of the European Working Group.

Jean Georges: The group works really well as the accompanying carers are great in supporting the attending people with dementia rather than speaking on their behalf. However, we have also realised that the views

and feedback of the attending carers and supporters may be different from those of people with dementia. For some EU projects, we organised separate focus groups for people with dementia and the carers, as researchers were looking for input and feedback from both groups. This convinced us though that Alzheimer Europe should create a second consultation and advisory mechanism solely involving carers and we are hoping to set up a European Carers' Working Group later this year.

“The group would not be able to function without the fantastic support provided by the carers and supporters who accompany the people with dementia who are members of the European Working Group.”

Iva Holmerová

Iva Holmerová: Although the Board of Alzheimer Europe already has a number of carers as members, these members are focusing on the governance of the association and monitoring the implementation of our work plans and budgets, rather than providing input on EU projects. The Board therefore felt that it would be important to ensure the views of carers are better taken into account in EU projects through the setting up of our new European Carers' Working Group and we will be able to build on the excellent work and model of our European Working Group of People with Dementia.

The group was originally formed to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia, and more recently, to contribute towards research projects in the context of Public Involvement. Do you think these goals are being achieved?

Iva Holmerová: The group has truly been excellent on both fronts and the focus has definitely shifted more towards Public Involvement activities in dementia research in the past years. The group was really helpful at the beginning in providing guidance on how best to portray the experience of dementia. Prior to the important feedback provided by our group, we often heard speakers, presenters and researchers at our conferences referring to victims, sufferers or even the demented. This is no longer the case and researchers have fundamentally changed the way they talk about people with dementia.

Jean Georges: I think that the group has been really influential in that regard. From researchers viewing people as patients or research participants, they are now looking at people with dementia as research partners whose input is needed to conduct research that is meaningful to them. In some instances, members of our group have contributed to research publications and co-authored articles in peer reviewed scientific journals. What amazing progress and results since 2012!

“From researchers viewing people as patients or research participants, they are now looking at people with dementia as research partners whose input is needed to conduct research that is meaningful to them.”

Jean Georges



Meeting to discuss setting up the EWGPWD, Glasgow, 2012. Jean Georges pictured, far right.

The Chairperson of the EWGPWD is also an ex-officio member on the Board of Alzheimer Europe, with full voting rights. How does this impact on the work of both Alzheimer Europe and of the EWGPWD?

Jean Georges: When we discussed setting up the group, we felt that it would be important to involve the group in the general governance of Alzheimer Europe and to let the group decide whom they would like to nominate to the Board. All too often, we saw Boards or projects select one person with dementia to participate in meetings, but I really felt uncomfortable with the idea of the Alzheimer Europe Board making this selection on their own. We therefore opted to first set up the group and let the group elect its chairperson who would then also join the Alzheimer Europe Board.

Iva Holmerová: This works really well in practice, as the chairperson of the group has his/her colleagues he/she regularly talks to, so that the feedback and contributions, that we receive, reflect the broader views of the whole group. On a personal note, I also have to say that we have been incredibly fortunate as we had fantastic representatives of the group with Helga Rohra, Helen Rochford-Brennan and Chris Roberts. They have been amazing advocates for the European Working Group, but also for people with dementia in general and made very important contributions to our work.

Do you have a few words you would like to say to the group's Executive and members, past and present?

Iva Holmerová: I have already singled out the three chairpersons of the group who have been real assets to Alzheimer Europe and our work. They have been tremendous representatives and really helped us turn our organisation into a more inclusive, representative and respectful organisation. I am truly grateful for their amazing contributions. However, they have been supported by a great group of people with dementia from various European countries and you will find the whole list of current and past members in this 10th Anniversary Supplement. I am happy as well that the Czech Alzheimer's Society was able to nominate Nina Baláčková to represent our organisation and country in this group.



Alzheimer Europe Board, 2016 (including EWGPWD 2012–2016 Chairperson Helga Rohra).



Alzheimer Europe Board, 2018 (including EWGPWD 2016–2020 Chairperson Helen Rochford-Brennan).

Jean Georges: Helga, Helen and Chris are indeed outstanding personalities and it has been a joy and pleasure to work with them, as well as the amazing group of members and their supporters. It would be impossible to thank all of them individually, but collectively they have all contributed to making Alzheimer Europe a stronger organisation. Without them, we would not have been able to achieve our number one strategic objective of truly giving a voice to people with dementia. Thanks all for your fantastic contributions.

“Without them, we would not have been able to achieve our number one strategic objective of truly giving a voice to people with dementia.”

Jean Georges

Evolution of the group and its Public Involvement work

Dianne Gove, Director for Projects and Ana Diaz, Project Officer, who support the European Working Group of People with Dementia (EWGPWD) on behalf of Alzheimer Europe, describe the evolution of the group and its work, particularly around Public Involvement in research. The group's Executive members also provide some insights.



Current EWGPWD Executive (Left to right Kevin Quaid, Chris Roberts, Bernd Heise), Luxembourg, 2022

What is Public Involvement?

Public Involvement (PI) is about involving people with dementia in the research process. It means doing research with rather than on or to people with dementia, and creating a partnership between researchers and the public/patients, whereby all contribute collaboratively in varying degrees towards the research process or the research output.

Alzheimer Europe is keen to promote the involvement of people with dementia in research in this way. This commitment to involving people with dementia was formalised in 2012 with the establishment of the European Working Group of People with Dementia (EWGPWD).

Involvement enables people with dementia to assist in identifying research priorities and the nature of the research to be undertaken, influence the direction and conduct of research, have their voices heard and, in so doing, contribute towards the quality, relevance and ethical conduct of research. It also enables researchers to benefit from the lived experience and perspectives of people with dementia.

The growing interest in PI in the field of dementia research also represents a positive step towards the inclusion of people with dementia in matters which are relevant to their lives and recognises the valuable contribution they can make to society.

Chris Roberts: "PI is about people affected by dementia being part of the research team, it is about being able to influence and make an impact on research. It is about doing nothing without ALL of us. It is about working together, it is about giving opinions, it is using our own expertise as we are experts by experience ourselves. We can bring a different perspective to the researchers and help to ensure that the research is more meaningful and suitable to the needs of people with dementia participating. It is also a right. Research empowers us and gives us hope as well."



Trees of Impact, created at the EWGPWD consultation for the PARADIGM project, Brussels, 2019.

What is needed to make it work?

It is essential that PI is conducted in such a way that it promotes a meaningful and active involvement of people with dementia and represents a true partnership between people with dementia, researchers and, when appropriate, policy-makers and other members of society.

PI activities should be planned, incorporated into the study design, budgeted for, documented and monitored. It should always be meaningful, rigorous and enhance the

research process. It should never amount to tokenism or 'box ticking' (i.e. either not using their input or involving them in an activity that is not needed simply to be able to claim that they were involved). Researchers should take all necessary measures to ensure the safety and well-being of people with dementia who are contributing towards PI. However, they should avoid being over-protective/paternalistic and be willing to challenge stereotypes about dementia which may hamper this kind of involvement.



ROADMAP project consultation with EWGPWD, Luxembourg, 2017

Bernd Heise: "There is still a lot of stigma and misconceptions about living with dementia and how people with dementia can contribute to society. It is important to change attitudes and the way we are often perceived. With appropriate support people with dementia can be part of this work and we make very valuable and relevant contributions."

Chris Roberts: "Researchers need to provide us with as much information as possible, about everything: the project itself, what it involves, what is expected from us, do we have to travel, what kind of support we would be getting from the team. Having the right information is going to help everybody, knowledge is power. The information should be very clear, in plain language and accessible, without acronyms, jargon or technical words. We need to receive all this information well ahead of the meeting. It is also important to receive feedback on how our opinions, our contributions, were used. It is great to have an acknowledgment for the work we do and to hear that we did make a difference."

Why is it important? Examples of topics that the EWGPWD has contributed to

Since 2014 members of the EWGPWD have been involved, in the context of PI, in several research projects. Their involvement is adapted to what is needed in each particular project and to what is meaningful and possible. Some of the topics which the group has contributed to include:

Reflecting about what matters to people with dementia

Members of the EWGPWD were involved in different projects looking at this topic. In 2014, they participated in a consultation about what people with dementia consider

to be meaningful aspects of psychosocial interventions, including the identification of outcome measures that truly mirror the benefits and possible drawbacks of these interventions.

They have also participated in two research projects (ROADMAP 2016–2018, RADAR-AD ongoing) which aimed to understand what functioning and the progression of the disease means to people with dementia, and how to measure and monitor it. Their feedback helped to identify outcomes that are important to people with dementia and their caregivers for assessing disease progression,

and what would constitute a meaningful delay in disease progression

Making research design more accessible and suitable for participants with dementia

The group has also participated in several research projects and provided advice on the materials or devices that participants in the study would be using or about the protocol that researchers were planning (e.g. linked to what participants would be asked to do, how participants could be best supported, the inclusiveness of the study etc.).

In this way, the members of the EWGPWD strive to promote inclusive and ethical research and sometimes challenge established scientific procedures. They encourage and motivate researchers to question the way that things are done, why they are done that way and whether they could be adapted to the needs of research participants with dementia. In some cases, they have highlighted very practical issues that could have affected people's willingness to join or remain in a particular study (e.g. linked to the frequency, timing, potential burden or invasiveness of various procedures and examinations, or to adequate signposting in research centres) or their wellbeing, which simply did not occur to researchers but were obvious to people with dementia. In others, they have asked for clarity regarding the necessity or rationale for certain inclusion and exclusion criteria (e.g. linked to place of residence, level of education, mobility, availability of a study partner), which were sometimes

linked to stereotypes and taken-for-granted assumptions about people with dementia (or older people in general) and sometimes linked to an imbalance between competing ethical requirements such as to respect and promote autonomy and to protect research participants from harm.

Changes are not always possible within the constraints of scientific research, or not immediately possible. However, the group plays an important role in highlighting obstacles to the inclusion of a broad range of people with dementia in research, in highlighting challenges and obstacles, and in refining certain research practices and procedures.

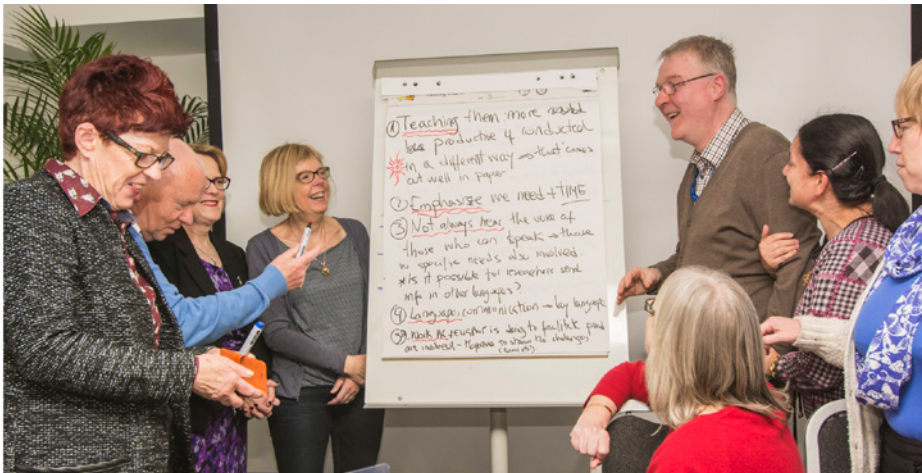
Promoting a more inclusive and ethical research

Members of the EWGPWD have participated in several discussions about the possible ethical

and social implications of different projects. They have addressed issues like privacy, data sharing, non-discrimination, stigma, vulnerability and helped to develop recommendations. They have also contributed towards AE annual reports on different ethical issues such as dementia as a disability, inclusive research and gender issues in dementia.

Raising awareness and changing attitudes among the research community of the value of involving people with dementia in research

There is still a lot of misconceptions about dementia and many people, don't fully understand what dementia is and how it affects the person. Sometimes researchers are not open, are afraid or do not have the skills to involve people with dementia in research as part of PI activities. Working closely with researchers, many of whom are also health care professionals, has helped to raise awareness of the relevant contributions and value that people with dementia can bring.



EWGPWD meeting, Brussels, 2016

What has changed over the years

Rethinking the terminology

When the EWGPWD started working in PI activities, the term Public and Patient Involvement (PPI) was frequently used. AE also used this term and in its first Position Paper on the topic, this was the term used.

Over the years, reference to "patients" has increasingly been considered as problematic in that a lot of people with dementia do not see themselves as patients and have voiced their concerns about being 'positioned' in this way. AE therefore decided to change this, and since 2019, we have used the term Public Involvement instead.



RADAR-AD project consultation with the EWGPWD, Luxembourg, 2019

Kevin Quaid: "My opinion about the word 'patient' is very strong. I am a patient when I visit a doctor or when I am at hospital, but when I am involved in a research I am a person with a brain disease, I am the expert about Lewy body dementia because I have it and I am living with it."

Strong emphasis on gender balance and inclusion

Membership of the EWGPWD has always been open to men and women with any kind of dementia and of any age. Over the years, the composition of the group has fluctuated in terms of those characteristics but recently, measures needed to be taken to attract more women to the group as the gender imbalance was quite extreme. Gender and age are, of course, not the only important personal characteristics.

The group is committed to being inclusive and to the promotion of diversity. Some members of the group have self-identified as being from certain marginalised or minority groups (e.g. in terms of sexual identity, ethnicity and religion). More work is needed, however, to attract people from marginalised groups. Although each member of the group is nominated by a national Alzheimer Association, members do not represent the views or positions of that association, and most importantly, they do not represent people with dementia (in general) in that country. Consequently, no one needs to be a “typical” or representative person from a specific country. Diversity is an advantage and the group is supportive and keen to adapt to particular needs that individual members, especially from marginalised groups, may have.

Kevin Quaid: “It is important that PI activities are accessible and inclusive. That people are aware about the opportunities to get involved. That they decide not to get involved because of financial issues or because they don’t have the confidence or support. Getting a diverse range of people involved is important so there are people with different experiences, perspectives and points of view. Involving people with different types of dementia means that you are getting experts opinions.”

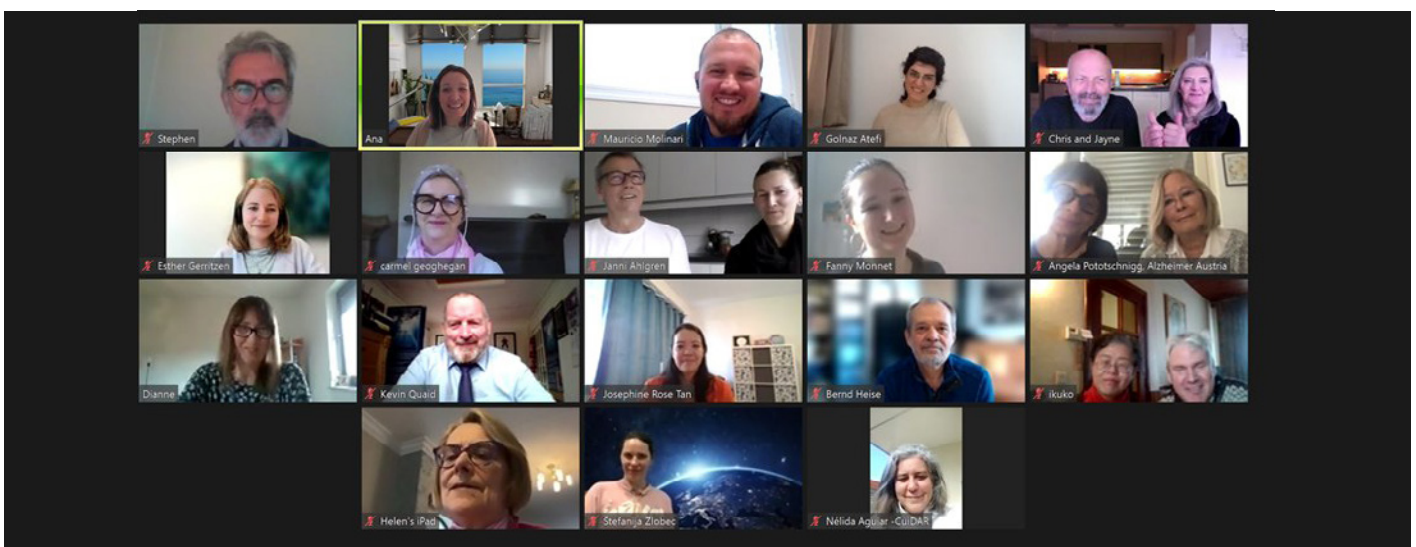
New ways of working

Another relevant change has been working remotely. The PI work of the EWGPWD was conducted in face-to-face meetings. Since the COVID 19 pandemic and related social distancing measures the work of the group was online. This was important for members as helped them to stay connected, to contribute to projects and was something many of them look forward to. However, working online involves also several challenges which need to be addressed and appropriate supports need to be provided to the person. Some of the aspects of the face-to-face meetings can not be replaced by online meetings.

Bernd Heise: “Face-to-face meetings are often easier for people with dementia. We can meet for longer time and longer discussions which helps to build relationships with other members of the group. There is time to get to know each other. Online work is possible but not every person with dementia is familiar or comfortable with computers or platforms like zoom, teams or Skype. Sometimes there is no one at home who can support the person to connect or if there are technical problems. The person may have difficulties to connect or to remember how to use the microphone or camera. Often this gets better once the person is used to the system. Online meetings require more concentration and focus and it can be challenging if there are many people in the meeting. An advantage is that people do not need to travel.”

A few final words

The EWGPWD has been constantly evolving since its beginnings in 2012, adapting to new situations and challenges, and acting on the experience and creativity of its members. Alzheimer Europe staff have evolved too, benefiting from the wisdom, experience and dedication of the group, in order to make PI a valuable and essential part of all the work that the organisation conducts and contributes to. We would therefore like to conclude this article with a huge thank you to the members of the EWGPWD, past, present and future!



10 years in pictures

These photos show the changing face of the group over the past 10 years, and include snapshots from meetings, conferences and some important and proud moments for the group.

2012



Meeting to discuss setting up the EWGPWD, Glasgow, 2012



Town hall reception for delegates at meeting to discuss setting up the EWGPWD, Glasgow, 2012

2013



EWGPWD at the Alzheimer Europe Conference, St Julian's, Malta, 2013



EWGPWD visiting a care home in Malta, 2013

2014



EWGPWD, 2014



EWGPWD Executive meeting (with supporters) Luxembourg, 2014

2015



EWGPWD meeting, Brussels, 2015



EWGPWD meeting, 2015

2016



Helen Rochford-Brennan accepting the Mano Amiga award on behalf of the EWGPWD, Leon, Spain, 2016



EWGPWD with HRH Princess Benedikte of Denmark, Alzheimer Europe Conference, Copenhagen, 2016

2017



Chris Roberts makes speech at 4th European Parliament of Persons with Disabilities, Brussels, 2017



Left to right MEP Nessa Childers, Helen Rochford Brennan, MEP Deirdre Clune, 2017, Brussels

2018



EWGPWD at the Alzheimer Europe Conference, Barcelona, Spain, 2018



Helga Rohra accepting EWGPWD plaque and giving farewell speech, European Parliament, Brussels, 2018

10 YEARS OF THE EWGPWD

2019



RADAR-AD project consultation with the EWGPWD, Luxembourg, 2019



EWGPWD meeting just before Christmas, Brussels, 2019

2020



EWGPWD meeting, Brussels, 2020

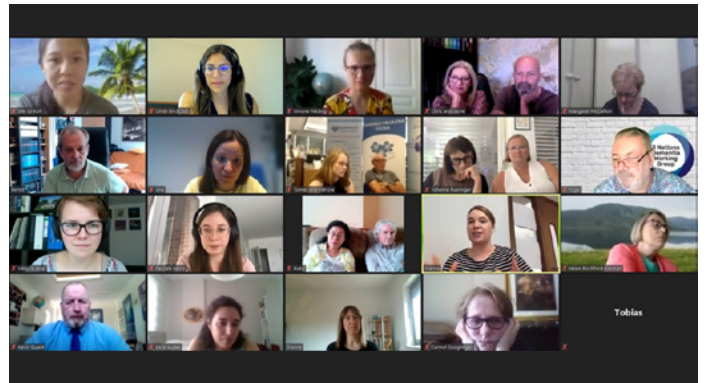


EWGPWD 2018–2020 group meeting, online, 2020

2021



Speakers at EWGPWD symposium, Alzheimer Europe Conference, online, 2021



DISTINCT project online consultation with EWGPWD, 2021

2022



Left to right: Helena Quaid, Ana Diaz, Kevin Quaid, Carmel Geoghegan, JPNP/Jpco-fuND2 Midterm Symposium, Brussels, 2022



EWGPWD meeting, Luxembourg, 2022

Life outside the group



Angela Pototschnigg (in red) attending The Diplomatic Academy of Vienna annual charity ball



Bojan Španja kayaking



Hilary Doxford and her husband Peter with their beloved dog



Idalina Aguiar celebrating her 80th birthday



Petri Lampinen going out cycling



Raoul Grönqvist playing his guitar



Rozell Snell dancing with her husband Brian



Stefan Eriksson hiking with his daughter Janni



Tomaž Gržinič sailing

European Working Group of People with Dementia members, 2012–2022

The group was launched by Alzheimer Europe and its member associations in 2012 and is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. They also consult on EU-funded research projects. The group operates independently and members elect their own Chairperson and Vice-Chairs. The Chairperson is also an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights.

Here is a list of all members of the group, since it first met in 2012:

Current Executive and members



Chris Roberts (Chairperson)
Country: United Kingdom (Wales)
Joined the group: 2016



Erla Jónsdóttir
Country: Iceland
Joined the group: 2020



Bernd Heise (Vice-Chairperson)
Country: Germany
Joined the group: 2018



Petri Lampinen
Country: Finland
Joined the group: 2017



Kevin Quaid (Vice-Chairperson)
Country: Ireland
Joined the group: 2020



Margaret McCallion
Country: United Kingdom (Scotland)
Joined the group: 2020



Idalina Aguiar
Country: Portugal
Joined the group: 2016



Danny McDonald
Country: United Kingdom (Scotland)
Joined the group: 2020



Stefan Eriksson
Country: Sweden
Joined the group: 2018



Angela Pototschnigg
Country: Austria
Joined the group: 2018



Tomaž Gržinič
Country: Slovenia
Joined the group: 2017



Helen Rochford-Brennan
Country: Ireland
Joined the group: 2014



Nigel Hullah
Country: United Kingdom (Wales)
Joined the group: 2020



Geert Van Laer
Country: Belgium
Joined the group: 2018

Former members



Stig Atle Aavik

Country: Norway

Years in the group: 2012–2014



Nina Baláčková

Country: Czech Republic

Years in the group: 2012–2018 and
from January 2020 until October 2020.



Hilary Doxford

Country: United Kingdom (England)

Years in the group: 2014–2016



Jean-Pierre Frognet

Country: Belgium

Years in the group: 2012 to 2014
Jean-Pierre passed away on 7 April 2016.



Raoul Grönqvist

Country: Finland

Years in the group: 2012–2016



Karin Gustafsson

Country: Sweden

Years in the group: 2016–2018



Amela Hajrić

Country: Bosnia and Herzegovina

Years in the group: 2016–2020



Carol Hargreaves

Country: United Kingdom (Scotland)

Years in the group: 2016–2020



Agnes Houston

Country: United Kingdom (Scotland)

Years in the group: 2012–2016



Miha Kastelic

Country: Czech Republic

Years in the group: 2018–2019



Thomas Maurer

Country: Switzerland

Years in the group: 2018–2020



Alv Orheim

Country: Norway

Years in the group: 2015–2017



Ingegärd Pousard

Country: Sweden

Years in the group: 2012–2014



Helga Rohra

Country: Germany

Years in the group: 2012–2016



Dermod Slevin

Country: Ireland

Years in the group: 2012–2014
Dermod passed away on 29 January 2018.



Rozel Snell

Country: Jersey

Years in the group: 2012–2015



Bojan Španja

Country: Slovenia

Years in the group: 2012–2015
Bojan passed away on 7 March 2022.



Daphne Wallace

Country: United Kingdom (England)

Years in the group: 2012–2014
Daphne passed away on 23 December 2020.



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