



Australian
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University



OUR HEALTH IN OUR HANDS
A TOOLKIT FOR COLLABORATION
BETWEEN PEOPLE LIVING WITH MS
AND RESEARCHERS

A strategic initiative of the Australian National University

ANU College of
Health & Medicine

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THE MS RESEARCH COLLABORATION TOOLKIT

Welcome to the MS research collaboration toolkit designed by, and for, people living with MS and researchers. It is a collection of materials to help people living with MS and researchers to understand each other and work well together.

Whether you are a person living with MS, or a person researching MS, the toolkit is designed to help you understand the perspectives of your collaborators, to work together effectively.

Some of the reasons you may find it useful to work with the toolkit are:

A person living with MS

- > You have been invited to join or are currently a member of a research governance board or reference group
- > You have been invited to join or are currently a member of a research team in your capacity as an expert about living with MS
- > You have been invited to participate in, or currently are, a participant in a research study about MS
- > You plan to attend an information session or research related event about findings from a research project

A researcher

- > You are in the early stages of planning a research project about MS and/or people living with MS
- > You are currently conducting a research project about MS and/or people living with MS
- > You want to share your findings with the MS community

The toolkit provides a set of materials that you can use as a researcher or as a person living with MS to enhance collaboration:

- > Principles of engagement
- > Getting to know one another
- > Desktop exercises

Each set of materials builds on the previous one. Some are designed to be used separately, and some are designed to be used in collaboration with people researching MS.

If you are interested in reading about how we developed the toolkit, we have included a section on our methods at the end of the toolkit.

WHY COLLABORATE?

It seems obvious that it is a good idea for people studying MS and people living with MS to talk together about research into MS.

When researchers talk to people who live with MS, they may have a clearer understanding of their priorities, and their struggles living with MS. When people living with MS talk to researchers, they may have a clearer understanding of how researchers focus on particular elements of MS and attempt to puzzle out a solution. When they talk together, they may be able to come to useful, informed ways of prioritising, structuring and refining research questions and developing effective ways to develop research solutions^{1,2}.

This approach is termed Patient and Public Involvement (PPI), or Consumer and Community Involvement in research. It describes research conducted **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.³ In Australia, PPI was pioneered at the Telethon Kids

Institute in Western Australia.⁴ In 2016 the NHMRC released a joint statement with the Consumer’s Health Forum of Australia on PPI in Research.⁵ The Statement clarified the importance of consumer involvement at all levels of research. The recommendations for researchers included:

- > minimise barriers to meaningful consumer and community involvement
- > build capacity of researchers, consumers and community members through training, mentoring and support

There are few examples of PPI in Multiple Sclerosis research,⁶ despite enthusiasm about the approach. Researcher-patient and public collaboration can be challenging to implement because of the complexity of scientific knowledge, differences in approaches to research, strategies to engage with consumers, and strategies to ensure accessibility. In developing this toolkit, it became apparent that these considerations all applied to MS research.

1 Tong A, Crowe S, Chando S, Cass A, Chadban SJ, Chapman JR, et al. Research Priorities in CKD: Report of a National Workshop Conducted in Australia. *Am J Kidney Dis.* 2015;66(2):212-222. Available from: <https://doi.org/10.1053/j.ajkd.2015.02.341>

2 McKenzie AE, Alpers K, Heyworth JS, Phuong C, Hanley B. Consumer and community involvement in health and medical research: evaluation by online survey of Australian training workshops for researchers. *Research Involvement and Engagement.* 2016;2:1-15. Available from: <https://doi.org/10.1186/s40900-016-0030-2>

3 INVOLVE – What is public involvement in research? Available from: <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>. Accessed May 2020.

4 Telethon Kids Institute [Internet]. <https://www.telethonkids.org.au/our-research/help-shape-our-research/> Accessed May 2020.

5 Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2016), Consumers Health Forum of Australia.

6 Tallantyre EC, Evangelou N, Bale C, Chaudhry BZ, Gray EH, LaRocca N, et al. Achieving effective patient and public involvement in international clinical trials in neurology. *Neurol Clin Pract* 2019;10.1212.

TYPES OF COLLABORATION

COLLABORATIVE RESEARCH TREE



Consumers can engage in research in a range of ways depending on their inclination and capacity. There is no “better” or more important mode of engaging in research, as everyone participates in the way that suits them and their life circumstances best.

Receivers of knowledge are consumers who are keen to be informed and updated on emerging research. They may attend seminars or receive regular updates through subscription sites such as Multiple Sclerosis News Today. All active researchers (co-researchers and advisors) are also receivers of knowledge.

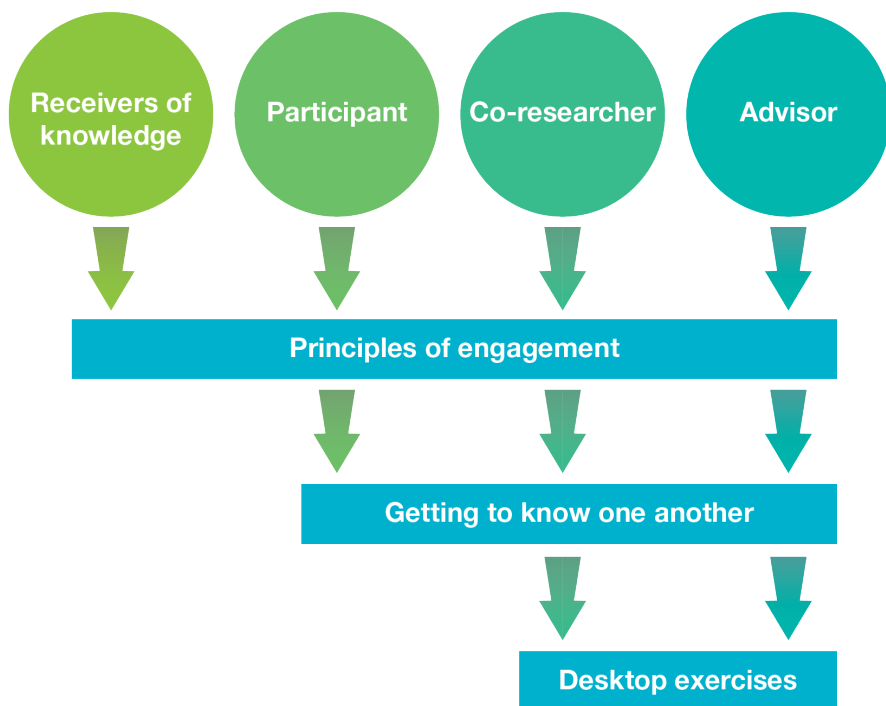
Participants engage in research by entering into clinical trials, or trials of devices, or focus groups or interviews. It is

an ethical requirement that participants are able to access the findings of research that they have been part of.

Co-researchers engage as members of research teams. They may be involved at the beginning of the research developing the methods, and collaborating with applications for funding. They may also enter later in the research cycle, helping to collect, and analyse data. It is important where possible that higher degree by research opportunities be available for people living with MS interested in research in this area.

Advisors hold more directive roles. For example, they may sit on Advisory Boards to determine research priorities or assess research outcomes, or on grant assessment panels.

USING THE TOOLKIT



We recommend that people living with MS interested in research begin with the **Principles of engagement**, which set out what people living with MS should expect when they engage in research.

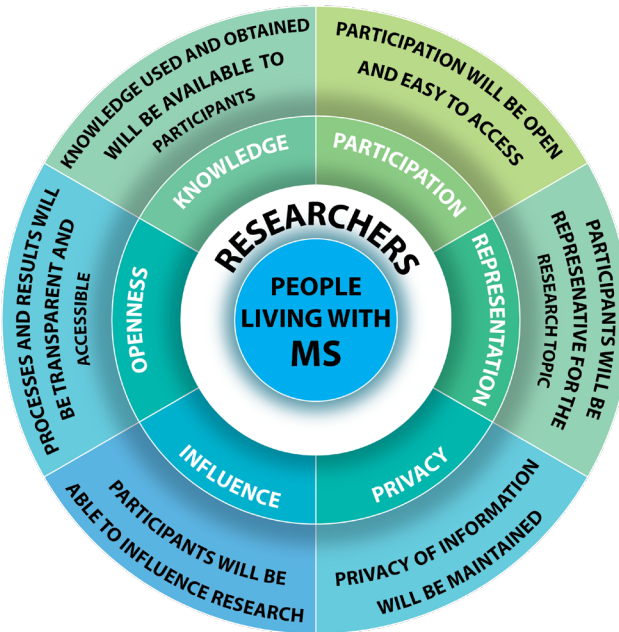
Participants, co-researchers and advisors can work together on **Getting to know one another** – a set of materials exploring different ways researchers and people living with MS may think about research and MS.

Co-researchers and advisors may find the **Desktop exercises**, which enable people living with MS to practise engaging in research and its oversight, of particular use.

PRINCIPLES OF ENGAGEMENT

When people living with MS become involved in research, they can feel as though they are entering a foreign land. Even people who are familiar with research, or who have been science or health care leaders, can find that the world of MS research is built by and for researchers studying MS rather than people living with MS.

It's useful to lay down some ground rules about what people living with MS should expect from research.



The wheel sets out the six key principles of collaboration: knowledge, privacy, influence, openness, participation, and representation.

Knowledge: The underlying hypotheses and research methods for MS Research are often complex and require higher order scientific literacy. To work effectively as co-researchers or advisors, people living with

MS must have a working mental model of the research question and the scientific thinking behind it. Researchers should be prepared to engage in developing the scientific literacy of researchers or advisors who do not have this background.

Privacy: Many people living with MS have kept their illness private from their workmates, or peers. This may impact

upon how they wish to, or are able to, engage in research. This should be respected by research administrators and researchers. As a standing ethical principle, people living with MS should not be identifiable without their express consent throughout the processes of research, and information should not be diverted for other purposes.

Influence: People living with MS who are co-researchers and advisors should, where relevant, be able to exert influence over the research. Failure to do this runs the risk of tokenism.

Openness: Processes of research should be clear to participants, and the results should be made available to them in ways that are accessible. Placing a summary on a dedicated website is of little use if the person does not have access to the internet or is not able to read or digest the research results. A number of different feedback mechanisms may be necessary.

Participation: Engaging in research as a participant, co-researcher and advisor can be logistically demanding. Researchers should be aware that transport and mobility limitations can impact on people's ability to engage in research. Other barriers include fatigue, and flare-up of illness symptoms. Researchers should test the accessibility of meeting rooms and have work-arounds such as remote conferencing for those who are fatigued or physically unable to attend.

Representation: Researchers should attempt to engage with groups of people who are often under-represented in research: young people, elders, people living with MS with young children, those who have invisible disabilities and may still be in the workforce, and those suffering from disabilities that limit their physical attendance.

Using the wheel

For people with MS: Reflecting on this wheel, how does the research you are engaged in meet these principles? If there are gaps in how they approach engagement, discuss with the researchers where improvements can be made to enhance engagement.

For researchers: Use the Table in Appendix A to assess your own project's inclusiveness for people living with MS.

GETTING TO KNOW ONE ANOTHER

Researchers and people living with MS are both committed to better knowledge about MS, and to reducing the burden of illness experienced by people living with MS. But this doesn't mean that they think the same way. This section addresses common points of misalignment between people living with MS and researchers.

1. Living with MS: Picturing my world

It can be difficult to articulate what it feels like to have MS. The images on this page were produced by two groups of people working together through a process of telling stories about their own experiences as they related to research, and living with MS. Their comments on the images are collated into collage poems. The images shine light on the perspectives of the researcher, the person living with MS, and the clinician. They attest to the complex relationships that all have with MS.



“

Frightened child

Sometimes I can see
my doctor is overwhelmed
by the disease.

It feels like we are
in the dark together.

It's not a comfort.

”



“

Ostrich

Putting your head in the sand.

We all do that on and off.

It's wanting not to know
even if you cook your head
in the sand.

”

“

Energetic explorer

The mountain's a metaphor
obviously
and the eagle
with huge wings
at the back of the explorer.
How small is the prey
compared to the
eagle and the explorer.

”



Illustrations by Dr Erin Walsh

2. Conversations between researchers and people living with MS

Drawing on the images and collaborative workshops with people living with MS, we developed a set of key domains where people living with MS and researchers often hold different philosophical views. We synthesised a series of statements under each key area.

The aim of this exercise is to articulate and compare fundamental philosophical positions held by researchers and people living with MS. There are no right or wrong answers. Participants are encouraged to reflect on how much they agree or disagree with the statements, and then to discuss them with a facilitator. Clarifying these through dialogue enables researchers and people living with MS to come to a better understanding of their different philosophical and practical stances.

Attitudes to time

I believe when it comes to MS, time is of the essence. Things must happen as soon as possible.

Everything takes time and it is important not to rush things.

Time is different when you have a chronic disease.

Purpose and goals

If there is a cure, science might find it.

There are cures, and I need to have realistic expectations.

Alleviating the symptoms of MS and improving quality of life is most important.

Risk and choice

Risk is something I often think about and actively manage.

I am responsible for my own risk.

I have choices in my risk.

Consent

My body and my data belong to me and not science.

I want to be able to provide consent as research changes.

Knowledge

I believe science and personal experience contribute to knowledge.

There are some things that science cannot explain now.

Using the collaboration toolkit:

Instructions on how to work with the toolkit are provided in Appendix B.

This dialogue method became the basis of a series of one on one conversations between researchers and people living with MS, which are available at anu.edu.au/MSToolkit.

3. Desktop exercises

Desktop exercises enable participants to take on different roles and consider the components of the principles for engagement and how they might apply in practice. The scenarios for three desktop exercises are included here. They are designed to be role playing exercises with participants playing the roles of Advisor, on a governance board, or Co-researcher or Participant. We have included a detailed example of the responses raised by one of the scenarios.

Case study 1: Test a new wearable sensor patch to measure fatigue through sweat

A new wearable sensor patch is developed to measure fatigue through chemicals in sweat. This has been used in the military and is good at detecting early signs of fatigue before the person detects it. It is proposed that this may be relevant for people living with MS. Should this study be pursued? What would be needed for participation?

Things to consider about the proposed study as an Advisor

While a person living with MS is an expert about their own experience of MS, being a member of a governance board may need some scientific knowledge to understand the research being proposed and/or undertaken. A useful exercise, and one that could build relationships with researchers, is to ask them to present their research proposal to the governance board in a format suitable for non-scientific experts and answer any questions about their work.

When assessing a project such as this, board members need to consider whether the research is of benefit: do people living with MS need such information about fatigue to manage their health? Is a form of early warning about the onset of fatigue useful or of benefit? Might it cause harm and what risks, if any, will it mitigate?

Are there any competing research ideas? If so, why might this project be better and how can the Board choose between them? How can the Board rank and prioritise symptoms and determine which is more worthy of investigation? The Board will have to agree on a way to do this.

It is also important to find out about any costs associated with participating and assessing the burden it may place on participants especially as fatigue is a common symptom.

A key concern is about the degree of influence a Board member has. What is in place to ensure a member has a voice within the Board and will be listened to; are they the only person living with MS on the Board? How will consensus be reached?

Things to consider as a co-researcher

A researcher may focus more on the co-design aspect. Are people living with MS involved in designing the study? They may also be interested in the source study and its methods and outcomes. Has this work already been done in this area? What are the real life benefits, effectiveness of the previous work?

Things to consider as a participant

Participants will be interested in knowing what the purpose of the study is, and what is required to participate. If they are personally invested in the project – perhaps because they have a high level of fatigue – they would need to understand if the project carried risks for them in terms of exacerbating fatigue; or if the researchers have included consideration of access barriers to research because of fatigue. Are they doing some outreach into people’s homes or work if that is suitable and easier? Participants will also wish to know how they can be informed of the results of the study, and when.

The diagram below outlines the types of infrastructure support needed to maximise involvement of people living with MS in research.



The same process of undertaking different role plays can be used for these two hypotheticals:

Case study 2: High levels of HHV 6 antibodies may indicate imminent relapse. Study to monitor people with MS for HHV 6 and check against symptoms

In one study, human herpes virus 6 antibodies are high before a relapse occurs. No one knows if this is a causation, or occurs for another reason. It is proposed to monitor people with MS for HHV 6 antibodies, checking against their symptoms. Should the study be pursued? What would be needed for participation?

Case study 3: Work with people living with MS to develop a model for MS friendly workplaces including retaining if needed

People living with MS often have to adapt their MS to the workplace rather than having the workplace adapt to them. The proposed study will develop with people with MS a model that ensures that people with MS are able to optimally work in their workplace. The model also includes a policy for retraining for people who can no longer work in their former workplace. Should the study be pursued? What would be needed for participation?

HOW WE DEVELOPED THE TOOLKIT

This toolkit was developed in collaboration with people living with MS. They are represented in this work as research participants, co-researchers, and as members of the Patient Health Experience Board which oversees our research.

The developmental process used a series of phased workshops and discussion groups aimed at recursively articulating, revising, reviewing, reframing, and trialing new tools. We encouraged people living with MS to articulate different positions that they may have among themselves, and researchers and people living with MS to engage in meaningful dialogue about their different perspectives and priorities.

We regard the differences that emerged with the community of people living with MS, and researchers, and between people living with MS and researchers as productive and useful. As was said multiple times through the development of this project, we are a community of inquiry,⁷ and being aware of our differences and our expectations makes us stronger in research together.

The research methods were eclectic and included:

- > A cartooning workshop for people living with MS, using collaborative storytelling and joint drawing⁸ to hone their focus on key relational and experiential elements of being involved in research.
- > Joint focus groups with researchers and people living with MS developing key principles of collaboration.
- > Expert group development of the collaborative toolkit drawing on the cartoons and the accounts of research.
- > Recording of one-on-one filmed dialogues between researchers and people living with MS using the collaborative toolkit questions.
- > Desktop exercises with people living with MS to finalise the Principles of Engagement document, and to clarify the infrastructure and supports articulated as necessary for different types of research, and research participation.

7 Peirce CS. The fixation of belief. In: Wiener P, editor. Charles Sanders Peirce: Selected writings. New York: Dover; 1958. p. 91-112.

8 Galvaan R. Getting the picture: The process of participation. In: de Lange N, Mitchell C, Stuart J, editors. Putting people in the picture: Visual methodologies for social change. Rotterdam, The Netherlands: Sense; 2007. p. 153-161.



N.B. Circles with purple borders were tasks undertaken with researchers and people living with MS participating in the research together.

The linkages between these methods are presented in the above figure.

Some of the research components directly tested and produced tools for this toolkit as an output, while others developed the tools. The linkages demonstrate how one research component was reviewed and incorporated into the results of other research components through the life of this project.

We thank the generous and open research participants, co-researchers and advisors for this project.

Justin Billing, Jacqueline Bradley, Anne Bruestle, Annie Brent, Katrina Chisholm, Janet Drew, Mark Elisha, Vanessa Fanning, Sally Hall, Jo Lane, Krishnan Murugappan, Helena Paul, Robin Vlieger, Richard Wilmot and all our workshop participants who live with MS or are researchers of MS and other scientific fields who gave their time and insights.

Long may we work together.

CONVERSATIONS



Mr Richard Willmot and Dr Jo Lane reflect together on how their values and priorities shape their approach to research.

If you would like to meet the research participants, you can watch our filmed interviews of conversations between people living with MS and researchers on the Our Health in Our Hands website.

The topics include:

- > Conversations about TIME
- > Conversations about RISK
- > Conversations about KNOWLEDGE
- > Conversations about GOALS
- > Conversations about CONSENT
- > What would you say to MS Researchers?

View all the videos here: anu.edu.au/MSToolkit

APPENDICES

Appendix A. Self-assessment table for researchers: Principles of engagement

This self-assessment tool is for researchers to review their own practice, against a series of indicators.

	Self-questions	Evidence
Participation	Have we ensured that participants can physically access meeting rooms?	
	Do we enable remote teleconferencing?	
	Are research facilities environmentally stable – not too hot or cold?	
	Do we enable people living with MS who have full time jobs to engage in research?	
Privacy	Do we have a policy known to our research administrative staff about maintaining privacy when contacting members?	
	Do we have a clear confidentiality policy available for people living with MS?	
Knowledge	Have we articulated a process for enhancing scientific literacy of participants, advisors and co-researchers?	
	What are the appropriate ways we disseminate research learnings to community?	
Representation	Have we undertaken a review of representativeness of our samples?	
	Are there any systematically unsampled, and potentially relevant, subpopulations?	
	How do we enhance their representation, when necessary?	
Influence	Do we create conditions to ensure participants' ideas and opinions will be valued and considered?	
	How can we ensure varied opinions are managed and dissenting voices heard?	
Openness	Do we assess whether or not participants understand the research project they are in?	
	Have we ensured that results are made available to participants in a timely and accessible fashion?	

Appendix B. Instructions for using toolkit for collaboration for researchers and people living with MS

This is a two-stage, facilitated exercise in which participants reflect on their personal views. If possible it would be useful to immediately compare these with those held by practitioners from different backgrounds. We recognise that individual psychological differences and personal experience may also influence answers, and these should not be discounted when they are raised in discussion.

You will need:

- > Sufficient copies of the toolkit for collaboration for each participant.
 - > Facilities for them to break into small groups.
 - > One discussion sheet (addressing 5 discussion areas) for each group of 5-6 participants.
- NB: If there are less than 12 participants, consider running the second stage with the facilitator using the discussion sheets.

Instructions:

Ensure that there are researchers and people living with MS distributed into groups of around 5-6 people. Try to ensure that there are no blocks of people who are already well known to one another. Put the discussion starter sheet face down in the middle of the group.

Pass around the toolkits for collaboration. Ask the group members to individually work through the toolkit, answering the questions quickly. Stress that there are no right or wrong answers, and none are presupposed in this toolkit. Allow about five minutes.

Turn over the discussion starter sheet.

Each person takes it in turn to read out one discussion starter. The group then discusses their attitudes to these issues. The aim is not to come to consensus but to air different viewpoints respectfully.

Each discussion should take about five minutes, and the group should not move onto the next discussion sheet till they have finished thinking through the previous discussion starter.

If you are doing this by yourself:

1. Look at the discussion starter questions.
2. Rate your thoughts through the toolkit questions.
3. Watch the interviews between researchers and people living with MS, considering the diversity of perspectives.

Appendix C. Toolkit for collaboration

Attitudes to time

I believe that when it comes to MS time is of the essence. Things must happen as soon as possible.

1	2	3	4	5
Don't agree				Strongly agree

Everything takes time and it is important not to rush things.

1	2	3	4	5
Don't agree				Strongly agree

Time is different when you have a chronic disease.

1	2	3	4	5
Don't agree				Strongly agree

Purpose and goals

If there is a cure, science might find it.

1	2	3	4	5
Don't agree				Strongly agree

There are cures, and I need to have realistic expectations.

1	2	3	4	5
Don't agree				Strongly agree

Alleviating the symptoms of MS, and improving quality of life is most important.

1	2	3	4	5
Don't agree				Strongly agree

Risk and choice

Risk is something I often think about and actively manage.

1	2	3	4	5
Don't agree			Strongly agree	

I am responsible for my own risk.

1	2	3	4	5
Don't agree			Strongly agree	

I have choices in my risk.

1	2	3	4	5
Don't agree			Strongly agree	

Consent

My body and my data belong to me and not science.

1	2	3	4	5
Don't agree			Strongly agree	

I want to be able to provide consent as research changes.

1	2	3	4	5
Don't agree			Strongly agree	

Knowledge

I believe science and personal experience contribute to knowledge.

1	2	3	4	5
Don't agree			Strongly agree	

There are some things that science cannot explain now.

1	2	3	4	5
Don't agree			Strongly agree	

Appendix D. Discussion starter questions

Attitudes to time

The time frame that researchers can have for time can be very different to the time frame that people living with MS have. The time that matters for our bodies may be different than the time that matters for discoveries for research.

Purpose and goals

Most researchers have a big picture goal for MS, even if they may not live to see it. A person living with MS may have a personalised goal, such as reducing burden of illness, or ensuring they don't pass it on to children. What would you say are the important goals of research?

Risk and choice

Your friend with MS has decided that she is going to go to Mexico for an experimental treatment. What would you say to her? Is there such a thing as a sensible risk?

Consent

Who owns the parts of the body that have been given for research? Is consent once given final? Or should it be reiterated if the project changes?

Knowledge

Is science as it currently is the best hope for a cure for MS? How do you feel when people say Western science is limited and there ought to be research into alternative treatments?

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

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