

ICMJE DISCLOSURE FORM

Date:

11/24/2024

Your Name:

Alyson Hillis

Manuscript Title:

How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities? A theory-informed qualitative evidence synthesis.

Manuscript Number (if known):

NIHR 130407 (May)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)						
Time frame: Since the initial planning of the work								
1	<div>All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.)  No time limit for this item.</div>	<div><div><input type="checkbox"/> None</div><table><tr><td>NIHR funded this work</td><td>Payments made to my institution</td></tr><tr><td></td><td></td></tr><tr><td></td><td>Click the tab key to add additional rows.</td></tr></table></div>	NIHR funded this work	Payments made to my institution				Click the tab key to add additional rows.
NIHR funded this work	Payments made to my institution							
	Click the tab key to add additional rows.							
Time frame: past 36 months								

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
2	Grants or contracts from any entity (if not indicated in item #1 above).	<input checked="" type="checkbox"/> None	
3	Royalties or licenses	<input checked="" type="checkbox"/> None	
4	Consulting fees	<input checked="" type="checkbox"/> None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input checked="" type="checkbox"/> None	
6	Payment for expert testimony	<input checked="" type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
7	Support for attending meetings and/or travel	<input checked="" type="checkbox"/> None	
8	Patents planned, issued or pending	<input checked="" type="checkbox"/> None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input checked="" type="checkbox"/> None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input checked="" type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
1 1	Stock or stock options	<input checked="" type="checkbox"/> None	
1 2	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> None	
1 3	Other financial or non-financial interests	<input checked="" type="checkbox"/> None	
<p>Please place an "X" next to the following statement to indicate your agreement:</p> <p><input checked="" type="checkbox"/> I certify that I have answered every question and have not altered the wording of any of the questions on this form.</p>			



## ICMJE DISCLOSURE FORM

**Date:** 10/1/2023

**Your Name:** Alison Richardson

**Manuscript Title:** How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities? A theory-informed qualitative evidence synthesis

**Manuscript Number (if known):** NIHR 130407 (May)

In the interest of transparency, we ask you to disclose all relationships/activities/interests listed below that are related to the content of your manuscript. "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the manuscript. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

The author's relationships/activities/interests should be defined broadly. For example, if your manuscript pertains to the epidemiology of hypertension, you should declare all relationships with manufacturers of antihypertensive medication, even if that medication is not mentioned in the manuscript.

In item #1 below, report all support for the work reported in this manuscript without time limit. For all other items, the time frame for disclosure is the past 36 months.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
<b>Time frame: Since the initial planning of the work</b>		
<b>1</b>	<div> <div>All support for the present manuscript (e.g., funding, provision of</div> <div> <input type="checkbox"/> None </div> </div>	
	NIHR funded this work.	Payments made to my institution

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
study materials, medical writing, article processing charges, etc.)  <b>No time limit for this item.</b>		Click the tab key to add additional rows.
Time frame: past 36 months		
2 Grants or contracts from any entity (if not indicated in item #1 above).	<input type="checkbox"/> None	
	Chief Investigator NIHR ARC Wessex	Payments made to institution
	Co applicant NIHR201542 – A multicentre randomised controlled trial (RCT) of a self-help cognitive behavioural therapy (CBT) intervention to reduce the impact of hot flush and night sweat (HFNS) symptoms in men with prostate cancer undergoing androgen deprivation therapy (ADT): MANaging symptoms during prostate CANcer treatment (MANCAN2)	Payments made to institution
	Co applicant NIHR133889 - Palliative Long-term Abdominal Drains Versus Repeated Drainage in Untreatable Ascites Due to Advanced Cirrhosis: A Randomised Controlled Trial (REDUCe 2 Study)	Payments made to my institution
	Co-applicant 15/46/02 - Methylphenidate versus placebo for fatigue in advanced cancer (MePFAC)	Payments made to institution
	Co-applicant NIHR150376 The FOLLOW UP study - a natural experiment comparing the clinical and cost-effectiveness of follow-up	Payments made to institution

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
		strategies after radical treatment for prostate cancer	
3	Royalties or licenses	<input checked="" type="checkbox"/> None	
4	Consulting fees	<input checked="" type="checkbox"/> None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input checked="" type="checkbox"/> None	



		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
6	Payment for expert testimony	<input checked="" type="checkbox"/> None	
7	Support for attending meetings and/or travel	<input type="checkbox"/> None	
		Member of international advisory board Karolinska Institute	Payments made to me personally
8	Patents planned, issued or pending	<input type="checkbox"/> None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input type="checkbox"/> None	
		Chair of REVAL:NIHR Rapid Service Evaluation team advisory group	Reimbursement of travel and subsistence costs
			.
			.
10	Leadership or fiduciary role in other board, society, committee	<input type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
	or advocacy group, paid or unpaid		
1 1	Stock or stock options	<input checked="" type="checkbox"/> None	
1 2	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> None	
1 3	Other financial or non-financial interests	<input checked="" type="checkbox"/> None	
		Secondment position as Head of Nursing Research, NHS England	Salaried employee (secondment)

Please place an "X" next to the following statement to indicate your agreement:

☒ I certify that I have answered every question and have not altered the wording of any of the questions on this form.



## ICMJE DISCLOSURE FORM

<b>Date:</b>	10/3/2023
<b>Your Name:</b>	Professor Carolyn Chew-Graham
<b>Manuscript Title:</b>	How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities A theory-informed qualitative evidence synthesis
<b>Manuscript Number (if known):</b>	NIHR 130407 (May)No

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	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)						
<b>Time frame: Since the initial planning of the work</b>								
<b>1</b>	<div style="display: flex; align-items: center;"> <input type="checkbox"/> <b>None</b> </div> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 10px;"> <tr> <td style="width: 50%; padding: 5px;">NIHR funded this work.</td> <td style="width: 50%; padding: 5px;">Funding to my institution (Keele University)</td> </tr> <tr> <td style="height: 20px;"></td> <td></td> </tr> <tr> <td style="height: 20px;"></td> <td style="padding: 5px; color: #ccc;">Click the tab key to add additional rows.</td> </tr> </table>		NIHR funded this work.	Funding to my institution (Keele University)				Click the tab key to add additional rows.
NIHR funded this work.	Funding to my institution (Keele University)							
	Click the tab key to add additional rows.							

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)								
<p>writing, article processing charges, etc.)</p> <p><b>No time limit for this item.</b></p>										
Time frame: past 36 months										
2	<p>Grants or contracts from any entity (if not indicated in item #1 above).</p>	<div> <input checked="" type="checkbox"/> None </div> <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>								
3	Royalties or licenses	<div> <input checked="" type="checkbox"/> None </div> <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>								
4	Consulting fees	<div> <input checked="" type="checkbox"/> None </div> <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>								
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or	<div> <input checked="" type="checkbox"/> None </div> <table border="1"> <tr> <td> <p>I have received honoraria for speaking at lectures on managing people with mental health problems in primary care from MIMS and RCGP. Payments made to me. Tax paid.</p> </td> <td></td> </tr> </table>	<p>I have received honoraria for speaking at lectures on managing people with mental health problems in primary care from MIMS and RCGP. Payments made to me. Tax paid.</p>							
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		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
	educational events	<div>I am Editor in Chief of the journal Health ExpectaPons. Payment to Keele University.</div>	
6	Payment for expert testimony	<div><input checked="" type="checkbox"/> None</div>	
7	Support for attending meetings and/or travel	<div><input checked="" type="checkbox"/> None</div>	
8	Patents planned, issued or pending	<div><input checked="" type="checkbox"/> None</div>	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<div><input checked="" type="checkbox"/> None</div>	
10	Leadership or fiduciary role in other board, society, committee	<div><input checked="" type="checkbox"/> None</div> <div>Membership of NIHR West Midlands ARC.</div>	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
	or advocacy group, paid or unpaid		
1 1	Stock or stock options	<input checked="" type="checkbox"/> None	
1 2	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> None	
1 3	Other financial or non-financial interests	<input checked="" type="checkbox"/> None	
<p>Please place an "X" next to the following statement to indicate your agreement:</p> <p><input checked="" type="checkbox"/> I certify that I have answered every question and have not altered the wording of any of the questions on this form.</p>			

## ICMJE DISCLOSURE FORM

**Date:** Click or tap to enter a date.

**Your Name:** Carl May

**Manuscript Title:** How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities? A theory-informed qualitative evidence synthesis

**Manuscript Number (if known):** NIHR 130407 (May)

In the interest of transparency, we ask you to disclose all relationships/activities/interests listed below that are related to the content of your manuscript. “Related” means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the manuscript. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

The author’s relationships/activities/interests should be defined broadly. For example, if your manuscript pertains to the epidemiology of hypertension, you should declare all relationships with manufacturers of antihypertensive medication, even if that medication is not mentioned in the manuscript.

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	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
Time frame: Since the initial planning of the work		
1	All support for the present manuscript	<input type="checkbox"/> None



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	(e.g., funding, provision of study materials, medical writing, article processing charges, etc.)  <b>No time limit for this item.</b>	NIHR funded this work.	Payments made to my institution
			Click the tab key to add additional rows.
Time frame: past 36 months			
2	Grants or contracts from any entity (if not indicated in item #1 above).	<input type="checkbox"/> <b>None</b>	
		Theme Lead: Innovation and Implementation, NIHR ARC North Thames.	Payments made to my institution
		MRC/NIHR EXTRA Study	Payments made to my institution
3	Royalties or licenses	<input checked="" type="checkbox"/> <b>None</b>	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)								
4	Consulting fees	<input checked="" type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
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6	Payment for expert testimony	<input checked="" type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
7	Support for attending meetings and/or travel	<input type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
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		<table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>											
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td>.</td></tr> <tr><td></td><td>.</td></tr> </table>									.		.
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10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>											
11	Stock or stock options	<input checked="" type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>											
12	Receipt of equipment, materials, drugs, medical writing,	<input checked="" type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>											

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
	gifts or other services		
<b>1</b>	Other financial or non-financial interests	<input checked="" type="checkbox"/> <b>None</b>	
<b>3</b>			
<p>Please place an "X" next to the following statement to indicate your agreement:</p> <p><input checked="" type="checkbox"/> I certify that I have answered every question and have not altered the wording of any of the questions on this form.</p>			



### ICMJE DISCLOSURE FORM

**Date:** 10/1/2023

**Your Name:** Professor Ellen Nolte

**Manuscript Title:** How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities? A theory-informed qualitative evidence synthesis

**Manuscript Number (if known):** NIHR 130407 (May)

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1	All support for the present manuscript	<input type="checkbox"/> None

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			Click the tab key to add additional rows.
Time frame: past 36 months			
2	Grants or contracts from any entity (if not indicated in item #1 above).	<input type="checkbox"/> None	
		NIHR206128 NIHR Policy Research Unit in Policy Innovation and Evaluation (PIRU)	PI
		NIHR158745 Embedding system change for people with long-term conditions: Learning from Primary Health Care reform in Georgia (ChangePHC Georgia)	Joint PI
		NIHR153580 SORT: Surgery Or RadioTherapy for early-stage cancer	Co-I
		NIHR134544 NIHR Global Research Group on Improving Hypertension Control in Rural Sub-Saharan Africa (IHCoR-Africa)	Co-I
		MRC-GACD Scaling up the Primary Health Integrated Care Project for Chronic Conditions in Kenya: an implementation research project	Co-I

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)								
3	Royalties or licenses	<input checked="" type="checkbox"/> None  <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
4	Consulting fees	<input checked="" type="checkbox"/> None  <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
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7	Support for attending meetings and/or travel	<input checked="" type="checkbox"/> None  <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									



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8	Patents planned, issued or pending	<input checked="" type="checkbox"/> None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input checked="" type="checkbox"/> None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input checked="" type="checkbox"/> None	
11	Stock or stock options	<input checked="" type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)						
1 2	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
1 3	Other financial or non-financial interests	<input checked="" type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
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## ICMJE DISCLOSURE FORM

<b>Date:</b>	10/1/2023
<b>Your Name:</b>	Professor Frances Mair
<b>Manuscript Title:</b>	How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities A theory-informed qualitative evidence synthesis
<b>Manuscript Number (if known):</b>	NIHR 130407 (May)

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2	Grants or contracts from any entity (if not indicated in item #1 above).	<input type="checkbox"/> None												
		<table border="1"> <tr> <td>Wellcome – Multimorbidity PhD Programme for Health professionals</td> <td>Payments made to my institution</td> </tr> <tr> <td>MRC - Multimorbidity in Africa MR/T037849/1- Increasing Understanding of the Patient Experience and Epidemiology. (MAfricaEE) and Exploring treatment burden and capacity for self care among patients with HIV/NCD multimorbidity in South Africa to inform interventions (EXTRA) MR/T03775X/1 and Healthcare and Socio-economic Impacts of COVID-19 on Patients with Diabetes in Tanzania and Kenya. Co-I MRC MR/V035924/1</td> <td>Payments made to my institution</td> </tr> <tr> <td>NIHR202020: Personalised Exercise-Rehabilitation FOR people with Multiple long-term conditions (multimorbidity)-The PERFORM trial.</td> <td>Payments made to my institution</td> </tr> <tr> <td>Digital Innovations and Diagnostics for Infectious Diseases in Africa. Innovate UK</td> <td>Payments made to my institution</td> </tr> <tr> <td>HIPPOCRATES – Promoting Early Identification and Improving Outcomes in Psoriatic Arthritis. 2021-26. Co-Investigator (Co-I) (Workpackage lead) Funder: Innovative Medicines Initiative (IMI 2)</td> <td>Payments made to my institution</td> </tr> <tr> <td>DynAIRx (AI for Dynamic prescribing optimisation and care integration in multimorbidity). Funded by UKRI</td> <td>Payments made to my institution</td> </tr> </table>	Wellcome – Multimorbidity PhD Programme for Health professionals	Payments made to my institution	MRC - Multimorbidity in Africa MR/T037849/1- Increasing Understanding of the Patient Experience and Epidemiology. (MAfricaEE) and Exploring treatment burden and capacity for self care among patients with HIV/NCD multimorbidity in South Africa to inform interventions (EXTRA) MR/T03775X/1 and Healthcare and Socio-economic Impacts of COVID-19 on Patients with Diabetes in Tanzania and Kenya. Co-I MRC MR/V035924/1	Payments made to my institution	NIHR202020: Personalised Exercise-Rehabilitation FOR people with Multiple long-term conditions (multimorbidity)-The PERFORM trial.	Payments made to my institution	Digital Innovations and Diagnostics for Infectious Diseases in Africa. Innovate UK	Payments made to my institution	HIPPOCRATES – Promoting Early Identification and Improving Outcomes in Psoriatic Arthritis. 2021-26. Co-Investigator (Co-I) (Workpackage lead) Funder: Innovative Medicines Initiative (IMI 2)	Payments made to my institution	DynAIRx (AI for Dynamic prescribing optimisation and care integration in multimorbidity). Funded by UKRI	Payments made to my institution
		Wellcome – Multimorbidity PhD Programme for Health professionals	Payments made to my institution											
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DynAIRx (AI for Dynamic prescribing optimisation and care integration in multimorbidity). Funded by UKRI	Payments made to my institution													

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
		Pharmacy Homeless Outreach Engagement Non-medical Independent prescribing Rx (PHOENix) community pharmacy based pilot randomised controlled trial. Co-I. NIHR133060	Payments made to my institution
		Development of a patient reported measure of treatment burden in stroke. CSO	Payments made to my institution
		Tailored Intervention At Home For Patients With Moderate-Very Severe COPD And Co-Morbidities By Pharmacists And Consultant Physicians (TICC PCP): Pilot Randomised Controlled Trial. Funder: CSO:HIPS/19/27	Payments made to my institution
		Prevention And Early Treatment Of COVID-19 Long Term Effects: A Randomised Clinical Trial Of Resistance Exercise. CSO Co-I.	Payments made to my institution
		Quantum Imaging for Remote Monitoring and Wellbeing and Disease in Communities. EPSRC	Payments made to my institution
		Multimorbidity in Arthritis and persistent musculoskeletal pain (MAP). Funder: Versus Arthritis	Payments made to my institution
3	Royalties or licenses	<input checked="" type="checkbox"/> None	
4	Consulting fees	<input checked="" type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input checked="" type="checkbox"/> None	
6	Payment for expert testimony	<input checked="" type="checkbox"/> None	
7	Support for attending meetings and/or travel	<input type="checkbox"/> None	
		Support from CSO to attend SAPC conference in my role as NRS Primary Care Network Co-lead.	
8	Patents planned, issued or pending	<input type="checkbox"/> None	
		SelfBACK app – developed as part of a Horizon2020 funded research programme	Payments made to my institution
9	Participation on a Data Safety Monitoring	<input type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)										
	Board or Advisory Board	<table border="1"> <tr> <td>Norwegian Primary Care Research Network – member of Advisory Board</td> <td>Institution reimbursed for travel and subsistence costs in relation to this work.</td> </tr> <tr> <td>Chair - NIHR funded AIM study (artificial intelligence/multimorbidity) 2021-ongoing</td> <td>Institution reimbursed for travel and subsistence costs in relation to this work.</td> </tr> <tr> <td>Member Programme Steering Committee of the NIHR Funded Programme Grant “Personalised Care for Parkinson’s Disease” PD-Care 2018-2023.</td> <td>Institution reimbursed for travel and subsistence costs in relation to this work.</td> </tr> <tr> <td>Member of THIS Institute Advisory Board</td> <td>Institution reimbursed for travel and subsistence costs in relation to this work.</td> </tr> <tr> <td>External Advisory Board Member NIHR School for Primary Care Research</td> <td>Institution reimbursed for travel and subsistence costs in relation to this work.</td> </tr> </table>	Norwegian Primary Care Research Network – member of Advisory Board	Institution reimbursed for travel and subsistence costs in relation to this work.	Chair - NIHR funded AIM study (artificial intelligence/multimorbidity) 2021-ongoing	Institution reimbursed for travel and subsistence costs in relation to this work.	Member Programme Steering Committee of the NIHR Funded Programme Grant “Personalised Care for Parkinson’s Disease” PD-Care 2018-2023.	Institution reimbursed for travel and subsistence costs in relation to this work.	Member of THIS Institute Advisory Board	Institution reimbursed for travel and subsistence costs in relation to this work.	External Advisory Board Member NIHR School for Primary Care Research	Institution reimbursed for travel and subsistence costs in relation to this work.	
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10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input type="checkbox"/> None <table border="1"> <tr> <td>Sit on MRC CARP Panel</td> <td>Reimbursed for time spent on this activity and travel and subsistence costs in relation to this work</td> </tr> <tr> <td></td> <td></td> </tr> <tr> <td></td> <td></td> </tr> </table>		Sit on MRC CARP Panel	Reimbursed for time spent on this activity and travel and subsistence costs in relation to this work								
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11	Stock or stock options	<input checked="" type="checkbox"/> None <table border="1"> <tr> <td></td> <td></td> </tr> <tr> <td></td> <td></td> </tr> <tr> <td></td> <td></td> </tr> </table>											
12	Receipt of equipment, materials, drugs, medical	<input checked="" type="checkbox"/> None <table border="1"> <tr> <td></td> <td></td> </tr> </table>											



		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
	writing, gifts or other services		
1 3	Other financial or non-financial interests	<input checked="" type="checkbox"/> None	
<p>Please place an "X" next to the following statement to indicate your agreement:</p> <p><input checked="" type="checkbox"/> I certify that I have answered every question and have not altered the wording of any of the questions on this form.</p>			

## Order of authors agreements and conflict of interest statements

### CMJE DISCLOSURE FORM

Date: 12/9/2024

Your Name: Katie Gallacher

Manuscript Title: How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities? A theory-informed qualitative evidence synthesis.

Manuscript Number (if known): NIHR 130407 (May)

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)						
Time frame: Since the initial planning of the work								
1	<div>All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.) No time limit for this item.</div>	<div><input type="checkbox"/> None</div> <table><tr><td>NIHR</td><td>Payments to my institution</td></tr><tr><td></td><td></td></tr><tr><td></td><td>Click the tab key to add additional rows.</td></tr></table>	NIHR	Payments to my institution				Click the tab key to add additional rows.
NIHR	Payments to my institution							
	Click the tab key to add additional rows.							
Time frame: past 36 months								
2	<div>Grants or contracts from any entity (if not indicated in item #1 above).</div>	<div><input type="checkbox"/> None</div> <table><tr><td>CSO 2023-2025 CAF/23/03 Exploring the relationship between burden of treatment and patient capacity on patient trajectories in patients with end-stage renal failure</td><td>Payments made to my institution</td></tr><tr><td></td><td></td></tr></table>	CSO 2023-2025 CAF/23/03 Exploring the relationship between burden of treatment and patient capacity on patient trajectories in patients with end-stage renal failure	Payments made to my institution				
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		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)								
		CSO 2022-2024, HIPS/21/13, Development and validation of a patient-reported measure (PRM) of treatment burden in stroke	Payments made to my institution								
		NHS Greater Glasgow and Clyde Endowment Funds, 2020-2021, GN19ST487. Content validity of a PRM of treatment burden in stroke	Payments made to my institution								
		Engineering and Physical Sciences Research Council, 2021 -2026, EP/T021020/1. Quantum-Inspired Imaging for Remote Monitoring of Health & Disease in Community Healthcare	Payments made to my institution								
		The Stroke Association Project Grant, SA PG 18\100067. Improving the implementation of supported stroke self-management: what does it look like and what makes it 'work' in different contexts	Payments made to my institution								
		Stroke Association Clinical Lectureship 2017-2023 TSA LECT 2017/01 Stroke Association	Payments made to my institution								
		The Stroke Association: PeRsonAlised Community based Telerehabilitation post StrokE to increase rehabilitation time and improve motor recovery: a feasibility study (PRACTISE) Ref: PG2S21\100006 2024-2027	Payments made to my institution								
		HIPPOCRATES European Commission 2021 - 2025	Payments made to my institution								
3	Royalties or licenses	<input checked="" type="checkbox"/> <b>None</b> <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
4	Consulting fees	<input checked="" type="checkbox"/> <b>None</b> <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>									
5	Payment or honoraria for lectures, presentations , speakers bureaus, manuscript writing or	<input type="checkbox"/> <b>None</b> <table border="1"> <tr> <td>University of Stavanger paid me for examining a viva Dec 2020</td> <td>Payment to me</td> </tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>		University of Stavanger paid me for examining a viva Dec 2020	Payment to me						
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		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)						
	educational events								
6	Payment for expert testimony	<input checked="" type="checkbox"/> <b>None</b> <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
7	Support for attending meetings and/or travel	<input type="checkbox"/> <b>None</b> <table border="1"> <tr> <td>Support from The Stroke Association to attend NADEGS meeting Carnoustie Jan 23, NAPCRG meeting in Phoenix Nov 22, UKSF meeting Liverpool Dec 22.</td> <td>Support for registration, travel and subsistence</td> </tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>		Support from The Stroke Association to attend NADEGS meeting Carnoustie Jan 23, NAPCRG meeting in Phoenix Nov 22, UKSF meeting Liverpool Dec 22.	Support for registration, travel and subsistence				
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8	Patents planned, issued or pending	<input type="checkbox"/> <b>None</b> <table border="1"> <tr> <td>In discussion with Mayo Clinic about copyright for a patient-reported measure of treatment burden we have adapted.</td> <td>No cost</td> </tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>		In discussion with Mayo Clinic about copyright for a patient-reported measure of treatment burden we have adapted.	No cost				
In discussion with Mayo Clinic about copyright for a patient-reported measure of treatment burden we have adapted.	No cost								
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input type="checkbox"/> <b>None</b> <table border="1"> <tr> <td>Chair Research Advisory Group for TRUSTED study.</td> <td>No reimbursement for participation</td> </tr> <tr> <td>Co-chair Research Advisory Group for QUEST study.</td> <td>No reimbursement for participation</td> </tr> <tr><td></td><td></td></tr> </table>		Chair Research Advisory Group for TRUSTED study.	No reimbursement for participation	Co-chair Research Advisory Group for QUEST study.	No reimbursement for participation		
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Co-chair Research Advisory Group for QUEST study.	No reimbursement for participation								
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input type="checkbox"/> <b>None</b> <table border="1"> <tr> <td>UKSF steering committee</td> <td>Travel re-imburse if in person but meetings have been remote for past 3 years</td> </tr> <tr> <td>UKSF conference planning committee</td> <td>Travel re-imburse if in person but meetings have been remote for past 3 years</td> </tr> <tr> <td>NACS</td> <td>Travel re-imburse if in person but meetings have been remote for past 3 years</td> </tr> </table>		UKSF steering committee	Travel re-imburse if in person but meetings have been remote for past 3 years	UKSF conference planning committee	Travel re-imburse if in person but meetings have been remote for past 3 years	NACS	Travel re-imburse if in person but meetings have been remote for past 3 years
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NACS	Travel re-imburse if in person but meetings have been remote for past 3 years								
11	Stock or stock options	<input checked="" type="checkbox"/> <b>None</b> <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
1 2	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input type="checkbox"/> None	
		Laptop from CSO grant	Purchased through grant by university on my behalf
		Digital recorder from CSO grant	Purchased through grant by university on my behalf
1 3	Other financial or non-financial interests	<input checked="" type="checkbox"/> None	
<p><b>Please place an "X" next to the following statement to indicate your agreement:</b></p> <p><input checked="" type="checkbox"/> I certify that I have answered every question and have not altered the wording of any of the questions on this form.</p>			

## ICMJE DISCLOSURE FORM

**Date:** 10/2/2023

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**Your Name:** Katja Camilla Gravenhorst

---

**Manuscript Title:** How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities? A theory-informed qualitative evidence synthesis.

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**Manuscript Number (if known):** NIHR 130407 (May)

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	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)						
<b>Time frame: Since the initial planning of the work</b>								
<b>1</b>	All support for the present manuscript (e.g., funding, provision of study materials, medical writing, article processing charges, etc.)  <b>No time limit for this item.</b>	<div style="border: 1px solid black; padding: 5px; margin-bottom: 10px;"> <input type="checkbox"/> <b>None</b> </div> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; padding: 5px;">NIHR funded this work</td> <td style="width: 50%; padding: 5px;">Payments made to my institution</td> </tr> <tr> <td style="height: 20px;"></td> <td></td> </tr> <tr> <td style="height: 20px;"></td> <td style="padding: 5px; color: gray;">Click the tab key to add additional rows.</td> </tr> </table>	NIHR funded this work	Payments made to my institution				Click the tab key to add additional rows.
NIHR funded this work	Payments made to my institution							
	Click the tab key to add additional rows.							
<b>Time frame: past 36 months</b>								

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
2	Grants or contracts from any entity (if not indicated in item #1 above).	<input type="checkbox"/> None	
3	Royalties or licenses	<input type="checkbox"/> None	
4	Consulting fees	<input type="checkbox"/> None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events	<input type="checkbox"/> None	
6	Payment for expert testimony	<input type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
7	Support for attending meetings and/or travel	<input type="checkbox"/> None	
8	Patents planned, issued or pending	<input type="checkbox"/> None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input type="checkbox"/> None	
10	Leadership or fiduciary role in other board, society, committee or advocacy group, paid or unpaid	<input type="checkbox"/> None	



		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)						
1 1	Stock or stock options	<input type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
1 2	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
1 3	Other financial or non-financial interests	<input type="checkbox"/> None <table border="1"> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> <tr><td></td><td></td></tr> </table>							
<p>Please place an "X" next to the following statement to indicate your agreement:</p> <p><input checked="" type="checkbox"/> I certify that I have answered every question and have not altered the wording of any of the questions on this form.</p>									



## ICMJE DISCLOSURE FORM

**Date:** 10/4/2023

**Your Name:** Mick Arber

**Manuscript Title:** How are service user and caregiver participation in health and social care shaped by lived experiences of illness trajectories, burdens of treatment, and social inequalities? A theory-informed qualitative evidence synthesis

**Manuscript Number (if known):** NIHR 130407 (May)

In the interest of transparency, we ask you to disclose all relationships/activities/interests listed below that are related to the content of your manuscript. "Related" means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the manuscript. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

The author's relationships/activities/interests should be defined broadly. For example, if your manuscript pertains to the epidemiology of hypertension, you should declare all relationships with manufacturers of antihypertensive medication, even if that medication is not mentioned in the manuscript.

In item #1 below, report all support for the work reported in this manuscript without time limit. For all other items, the time frame for disclosure is the past 36 months.

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
<b>Time frame: Since the initial planning of the work</b>		
<b>1</b>	<div> <div>All support for the present manuscript (e.g., funding, provision of study materials, medical</div> <div> <input type="checkbox"/> None </div> </div>	
	<div> <div>London School of Hygiene &amp; Tropical Medicine (LSHTM)</div> <div></div> </div>	<div> <div>I am employed by York Health Economics Consortium Ltd (YHEC). YHEC were contracted by LSHTM to conduct literature searches and initial screening as part of this work.</div> <div></div> </div>

	Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
writing, article processing charges, etc.)  <b>No time limit  for this item.</b>		Click the tab key to add additional rows.
Time frame: past 36 months		
2	Grants or contracts from any entity (if not indicated in item #1 above).  <input checked="" type="checkbox"/> None	
3	Royalties or licenses  <input checked="" type="checkbox"/> None	
4	Consulting fees  <input checked="" type="checkbox"/> None	
5	Payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or  <input checked="" type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
	educational events		
6	Payment for expert testimony	<input checked="" type="checkbox"/> None	
7	Support for attending meetings and/or travel	<input checked="" type="checkbox"/> None	
8	Patents planned, issued or pending	<input checked="" type="checkbox"/> None	
9	Participation on a Data Safety Monitoring Board or Advisory Board	<input checked="" type="checkbox"/> None	
10	Leadership or fiduciary role in other board, society, committee or advocacy	<input checked="" type="checkbox"/> None	

		Name all entities with whom you have this relationship or indicate none (add rows as needed)	Specifications/Comments (e.g., if payments were made to you or to your institution)
	group, paid or unpaid		
1 1	Stock or stock options	<input checked="" type="checkbox"/> None	
1 2	Receipt of equipment, materials, drugs, medical writing, gifts or other services	<input checked="" type="checkbox"/> None	
1 3	Other financial or non-financial interests	<input checked="" type="checkbox"/> None	
		York Health Economics Consortium Ltd	I am an employee of York Health Economics Consortium Ltd, the company contracted by LSHTM to conduct literature searches and initial screening as part of this work.

Please place an "X" next to the following statement to indicate your agreement:

☒ I certify that I have answered every question and have not altered the wording of any of the questions on this form.