

# Change in disability in activities of daily living over time among adults with advanced respiratory disease during the COVID-19 pandemic

<b>Submission date</b> 30/11/2020	<b>Recruitment status</b> No longer recruiting	<input type="checkbox"/> Prospectively registered <input checked="" type="checkbox"/> Protocol
<b>Registration date</b> 14/12/2020	<b>Overall study status</b> Completed	<input type="checkbox"/> Statistical analysis plan <input checked="" type="checkbox"/> Results
<b>Last Edited</b> 02/02/2026	<b>Condition category</b> Respiratory	<input type="checkbox"/> Individual participant data

## Plain English summary of protocol

### Background and study aims

The researchers are very interested in finding out more about how people with advanced lung cancer or respiratory disease manage daily activities (e.g. washing, dressing, shopping, and walking) and how this changes over several months during the Coronavirus (COVID-19) pandemic. This is so they can identify when people with these conditions may become unable to manage everyday activities, what may cause them to have more difficulty (e.g. breathlessness) and what might help to improve their independence, in order to guide clinical practice and service provision.

This is important because people are living longer with advanced lung cancer or respiratory disease due to an ageing population and advances in treatment prolonging survival. This may change the illness trajectory of these conditions in terms of prolonging symptoms and disability. Disability in advanced disease has a specific effect on a persons' ability to perform daily activities, limiting a patients' independence and quality of life, impacting on care needs.

### Who can participate?

Adults with a diagnosis of either advanced non-small cell lung cancer or respiratory disease (chronic obstructive lung disease (COPD) or interstitial lung disease (ILD))

### What does the study involve?

This is an observational study of patients with advanced lung cancer or respiratory disease looking at how disability changes over time in daily activities (e.g. washing, dressing, shopping, walking) and associated factors including symptoms and social isolation. The researchers are recruiting from hospital and hospice in/outpatient settings throughout the UK and will be following participants for 6 months. Following consent, participants will complete a baseline questionnaire upon enrolment over the telephone and a series of monthly postal questionnaires over 6 months.

What are the possible benefits and risks of participating?

This research does not involve any changes to patient care, and so patients are unlikely to benefit personally from taking part, though participation may help to improve the care of others in future. The risks to taking part are very small, this research will not in any way affect the standard of clinical care participants might receive, care options, or any relationships they have with any staff or researchers. Some people may find some of the questions upsetting, but participants can choose not to answer questions if they do not want to and can withdraw at any time.

Where is the study run from?

Cicely Saunders Institute King's College London (UK)

When is the study starting and how long is it expected to run for?

January 2020 to August 2021

Who is funding the study?

National Institute for Health Research (NIHR) (UK)

Who is the main contact?

Lucy Fettes

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## Contact information

### Type(s)

Scientific

### Contact name

Miss Lucy Fettes

### ORCID ID

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### Contact details

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Public

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## **Additional identifiers**

### **Clinical Trials Information System (CTIS)**

Nil known

### **Integrated Research Application System (IRAS)**

271894

### **ClinicalTrials.gov (NCT)**

Nil known

### **Protocol serial number**

IRAS 271894

## **Study information**

### **Scientific Title**

Comparing disability in activities of daily living over time among adults with advanced lung cancer or respiratory disease during the COVID-19 pandemic

### **Acronym**

DIScOVER

### **Study objectives**

1. People with advanced lung cancer develop greater disability in activities of daily living over time than people with advanced respiratory disease
2. Symptom severity is positively associated with subsequent disability in activities of daily living
3. Use of an assistive device is positively associated with increased independence in activities of daily living
4. Social isolation is positively associated with increased dependence in activities of daily living

### **Ethics approval required**

Old ethics approval format

### **Ethics approval(s)**

Approved 11/02/2020, London - Camberwell St Giles Research Ethics Committee (Level 3, Block B, Whitefriars, Lewins Mead, Bristol, BS1 2NT, UK: +44 (0)207104 8204; nrescommittee.london-camberwellstgiles@nhs.net), REC ref: 19/LO/1950

## **Study design**

Multi-center longitudinal prospective cohort study

## **Primary study design**

Observational

## **Study type(s)**

Other

## **Health condition(s) or problem(s) studied**

Exploring disability in patients with non-small cell lung cancer or respiratory disease

## **Interventions**

Sample: advanced no small cell cancer or respiratory disease

Recruitment sites: hospital lung cancer and respiratory inpatients and outpatient clinics; hospice /palliative care inpatients, outpatients, or community teams.

Outcome variable: disability in activities of daily living

Explanatory variables: symptom burden; assistive device use; social isolation

Outcome measures: Barthel Index; Lawton Brody IADL scale; WHO Disability Assessment Scale (WHODAS 2.0); Palliative Outcomes Scale-Symptoms; Chronic Disease Self-Efficacy Social Support Sub-scale

Data collection: Baseline self-reported questionnaire via telephone and monthly postal survey for 6 months or until death.

## **Intervention Type**

Other

## **Primary outcome(s)**

Disability (independence) in basic activities of daily living measured using the Barthel Index at baseline and monthly for 6 months

## **Key secondary outcome(s)**

1. Disability (independence) in instrumental activities of daily living measured using the Lawton Brody IADL scale at baseline and monthly for 6 months
2. Disability severity in activities of daily living measured using the WHO Disability Assessment Scale (WHODAS 2.0) at baseline and monthly for 6 months
3. Symptom burden measured using the Palliative Outcomes Scale-Symptoms (POS-S) at baseline and monthly for 6 months
4. Confidence to receive social support measured using the Chronic Disease Self-Efficacy Social Support Sub-scale at baseline

## **Completion date**

01/08/2021

## **Eligibility**

**Key inclusion criteria**

1. Patients aged >18 years
2. Advanced lung cancer or respiratory disease as defined by one of the following:
  - 2.1. Lung cancer: Inoperable stage III or IV non-small cell lung cancer
  - 2.2. Chronic Obstructive Lung Disease (COPD): Severe or very severe stages of COPD according to the criteria set by the Global Initiative for Chronic Obstructive Lung Disease (GOLD): stage III (FEV1/FVC <70%.  $30\% \leq \text{FEV1} < 50\%$  predicted with or without chronic symptoms (cough, sputum production)) and stage IV (FEV1/FVC <70%. FEV1 <30% predicted plus chronic respiratory failure)
  - 2.3. Interstitial lung disease (ILD): Carbon monoxide transfer factor (TLCO/DLCO) level of <40% or FVC <50% predicted
3. Patients with capacity to consent
4. Patients with ability to understand and complete a questionnaire in English
5. Life expectancy of >1 month as assessed by the person taking consent

**Participant type(s)**

Patient

**Healthy volunteers allowed**

No

**Age group**

Mixed

**Lower age limit**

18 years

**Upper age limit**

100 years

**Sex**

All

**Total final enrolment**

201

**Key exclusion criteria**

1. Patients aged <18 years
2. Patients who lack the capacity to consent
3. Patients who lack the ability to understand and complete a questionnaire in English
4. Life expectancy of <1 month as assessed by the person taking consent

**Date of first enrolment**

01/03/2020

**Date of final enrolment**

28/02/2021

**Locations**

**Countries of recruitment**

United Kingdom

England

**Study participating centre**

**Princess Royal University Hospital (Kings College London NHS Trust)**

Farmborough Common

Orpington

England

BR6 8ND

**Study participating centre**

**Nottingham University City Hospital**

Hucknall Road

Nottingham

England

NG5 1PB

**Study participating centre**

**Macclesfield District General Hospital**

Victoria Road

Macclesfield

England

SK10 3BL

**Study participating centre**

**South Tyneside District Hospital (South Tyneside and Sunderland NHS Foundation Trust)**

Harton Lane

South Shields

England

NE34 0PL

**Study participating centre**

**Royal Cornwall Hospital**

Treliske

Truro

England

TR1 3LJ

**Study participating centre**  
**Medway NHs Foundation Trust**  
Windmill Road, Gillingham  
Kent  
England  
ME7 5NY

**Study participating centre**  
**St Christopher's Hospice**  
51-59 Lawrie Park Road  
London  
England  
SE26 6DZ

**Study participating centre**  
**St Michael's Hospice**  
25 Upper Maze Hill  
Saint Leonards-on-sea  
England  
TN38 0LB

**Study participating centre**  
**St Barnabas Hospice**  
Titnore Lane  
Worthing  
England  
BN12 6NZ

**Study participating centre**  
**Worthing Hospital (Western Sussex NHS Foundation Trust)**  
Lyndhurst Road  
Worthing  
England  
BN11 2DH

**Study participating centre**  
**York Hospital**  
Wigginton Road  
York  
England  
YO13 8HE

**Study participating centre**  
**Guys and St Thomas' NHS Foundation Trust**  
Great Maze Pond  
London  
England  
SE1 9RT

**Study participating centre**  
**Asthma UK and British Lung Foundation Partnership**  
18 Mansell Street  
London  
England  
E1 8AA

## **Sponsor information**

**Organisation**  
King's College Hospital NHS Foundation Trust

**ROR**  
<https://ror.org/01n0k5m85>

**Organisation**  
King's College London

## **Funder(s)**

**Funder type**  
Government

**Funder Name**  
National Institute for Health Research

**Alternative Name(s)**  
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR



**Funding Body Type**  
Government organisation

**Funding Body Subtype**  
National government

**Location**  
United Kingdom

## Results and Publications

**Individual participant data (IPD) sharing plan**  
Data will be archived in a secure unit at the Cicely Saunders Institute King’s College London for 7 years, which is specified in the participant information sheet.

**IPD sharing plan summary**  
Stored in repository

**Study outputs**

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">Results article</a>		12/08/2021	04/01/2024	Yes	No
<a href="#">Results article</a>		10/12/2023	21/01/2025	Yes	No
<a href="#">HRA research summary</a>			28/06/2023	No	No
<a href="#">Other publications</a>	Secondary analysis	18/12/2025	02/02/2026	Yes	No
<a href="#">Participant information sheet</a>	version V3.0	06/05/2020	04/01/2021	No	Yes
<a href="#">Protocol file</a>	version V2	06/05/2020	04/01/2021	No	No