Understanding
Patient Data

Resource quick-guide

May 2019 v1.0

Understanding Patient Data (UPD) is an independent initiative hosted at Wellcome. We support better conversations about how health and care data is used. We work with patients, charities and healthcare professionals to champion responsible uses of health and care data.

We believe:

Using patient data could help save lives

Patient data should be kept safe and secure, to protect privacy

Everyone should be able to find out about how patient data is used

Watch our video explaining why we need to talk about patient data.

Want to know more? Find out about UPD.

This is a quick-guide to help navigate UPD resources for talking about how health data is used in UK health services and beyond. It includes **key messages** and **resource links** to help you respond to questions and concerns about the use of patient data.

UPD believes patients and publics should not just be informed, but should be part of meaningful conversations around how health data is used.

To get the most from this guide, we encourage you to consider your own audiences and how best to provide the information they'd want. UPD resources are a starting point to edit and adapt to your own specific needs.

Excluding reports, UPD resources are freely available on a CC-BY licence.

If you have any feedback or comments to help us improve this guide, please let us know at hello@understandingpatientdata.org.uk

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TOP 5 RESOURCES

Resource	Most likely to help people looking for…
Data citation	…a way to acknowledge the use of patient data.
Best words to use / What does 'anonymised' mean?	…how to describe patient data to audiences who are less familiar with technical language.
Uses of patient data wheel	…a visual tool to show the range of ways patient data is used to improve health, care and services through research and planning.
Data saves lives animations / Video case studies	…engaging animations and short videos describing stories of how patient data can save lives.
Case Studies	…examples of how patient data is used in research and planning for public benefit.

PUBLIC ATTITUDES, ENGAGEMENT ACTIVITIES & REPORTS

Resource	Most likely to help people interested in…
Summaries and key themes from public attitudes research	…understanding how people feel about the use of patient data.
Public attitudes to new technologies	…emerging understanding of public attitudes to new technologies using patient data.
Public and patient engagement activities	…good practice, tips and advice from existing engagement activities.
Healthcare and data: how do we get it right?	…the barriers and opportunities around using patient data in health and care.
Data for public benefit	…a framework to help define, assess and evaluate what data use for “public benefit” means in practice.

While there is no single “public”, common questions and concerns have emerged from qualitative research with patients and publics on the use of patient data.

What is patient data?

Why is it important to use patient data?

Can I be identified from the data?

Why do companies need to access patient data?

What’s allowed and not allowed?

What safeguards are in place to protect patient data?

What choices do I have about how patient data is used?

What happens to patient data and who sees it?

What are the risks around how patient data is used?

Click on a speech bubble to jump to guidance on how to respond.

This guide is designed to help you think about what to consider to create clear, meaningful answers to these common questions and concerns.

Find out more about 1. Public attitudes to the use of patient data.
2. Good practice from existing patient and public engagement activities 3. Frequently asked questions

01

WHEN EXPLAINING WHAT PATIENT DATA IS

It’s important to be clear what kind of data you mean.

For example, whether it’s data:
- about one person or many
- that includes information that could identify an individual.

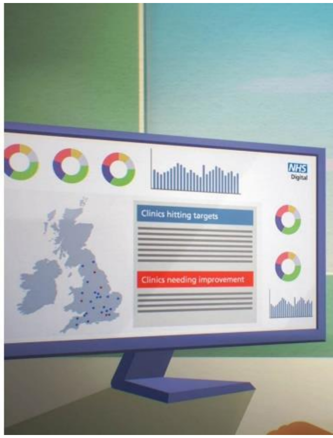
Try to include examples such as diagnosis, medication, age range, postcode region.

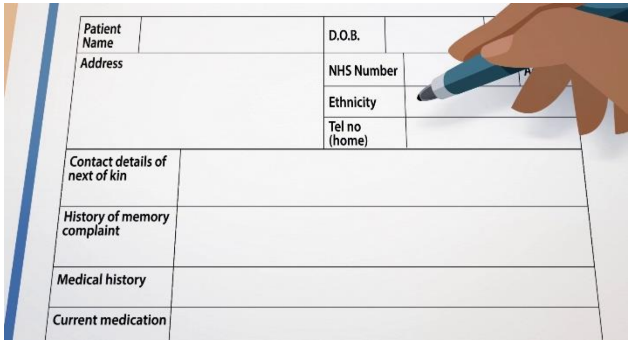
Consider that the phrase “patient data” can be about many things

For example:

it can mean data about many people
Patient data can be made up of data extracted from the health records of many different people that has been pooled together, for example to produce statistics.

or about one person (“individual level data”)
Patient data can be about individual people, whether they are identifiable from the data or not.





Patient Name		D.O.B.	
Address		NHS Number	
		Ethnicity	
		Tel no (home)	
Contact details of next of kin			
History of memory complaint			
Medical history			
Current medication			

Patient data becomes **Confidential Patient Information** when it combines something that identifies a patient with information about their health. For example, information about the medication someone is taking together with their name, contact information, date of birth, or next-of-kin information.

Find out more about 1. The best words to use when talking about patient data.
2. An introduction to people’s views on what we should be talking about around patient data.

Consider that patient data may be included in:

- **GP records**
- **Clinical audits e.g. National diabetes audit**
- **Disease registries e.g. Cancer registry**
- **Council records e.g. number of people receiving care at home**
- **Diagnostic imaging datasets e.g. fMRI scans**
- **Prescribing databases e.g. antibiotic prescription rates**
- **Commission reporting and evaluation e.g. service improvement measures**
- **Patient surveys e.g. Patient Reported Outcome Measures (PROMs)**
- **Hospital Episode Statistics e.g. A&E admissions and outpatient appointments**

Other specialists like dentists, physiotherapists and psychologists also create records. Sensitive information is also collected in social care settings.

Other types of data include information collected during clinical trials and cohort studies. Data generated by people might also be considered patient data; for example, health app data, fitness trackers or patient surveys.

02

WHEN EXPLAINING WHY IT IS IMPORTANT TO USE PATIENT DATA

Remember, most people are comfortable with patient data about them being used by health and care professionals as part of their individual care.

But, people are less familiar with the benefits of using patient data for improving health, care and services through research and planning.

Where possible use examples and case studies to describe how public benefits can arise from using data.

Remember that patient data should be used to help people get the best individual care

Good quality information is essential to inform our clinical care. A person’s whole care team, whether in a GP practice, a hospital or a care home, need to have access to up-to-date information to inform their treatment, and to provide the best care.

Every patient should have access to information about their own healthcare, to check information is accurate and to use it to help manage their health.

Find out more about 1. The improving record sharing in health and social care animation explaining how good information sharing can benefit patients. 2. Patient access to health and care records.

Remember that:

There is low awareness of how data is used to improve health, care and services through research and planning.

People don't necessarily relate the benefits of research and planning to themselves, their health or the health of their loved ones.

Where possible use examples to describe in clear, accessible ways how data can be used for public benefit, and how data could save lives.

Find out more about 1. Why it's important to use patient data including a printable summary of the different types of benefits shown in the wheel above. 2. Case studies describing a range of ways patient data can be used. 3. The bigger picture animation explaining how data saves lives. 4. Patient journey animations showing a range of ways data is used to improve care. 5. Short videos showing researchers, clinicians and patients talk about the benefits of using patient data.

03

WHEN EXPLAINING WHAT HAPPENS TO PATIENT DATA AND WHO SEES IT

Be open. People are unlikely to know about the different types of organisations that use patient data, why they use patient data, or how access to data works.

Be aware people may want reassurances, including that:

- a patient’s full record will only be seen by healthcare professionals who are directly involved in their care.
- there are strict controls on how anyone else can access patient data.
- patient data can only be used beyond individual care if there is a public benefit.

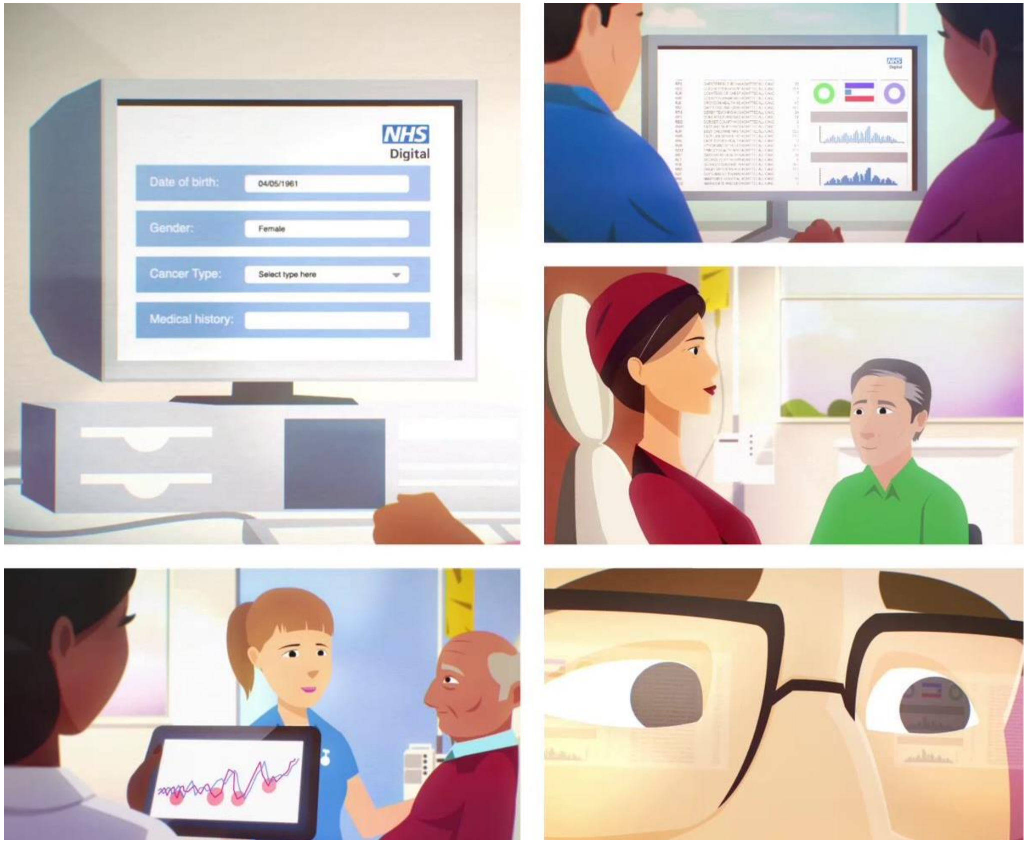
Remember the types of organisations that can use patient data include:

NHS providers and commissioners who use data to monitor trends and patterns in population health, hospital and care activity, to assess how care is provided, and to support local service planning.

University researchers who use data to understand more about the causes of disease, to develop new ways of diagnosing illness or to identify ways to develop new treatments.

Charities who use data to evaluate services, advocate for patient communities and identify ways to improve care.

Companies who use data for many reasons, for example if they are partnering with the NHS, developing drugs or providing services.



Find out more about 1. How and why UK universities use patient data (animation by Connected Health Cities and the Farr Institute). 2. What data is used by researchers. 3. Examples of different organisations using patient data in our case studies. 4. What to consider when explaining why companies access patient data.

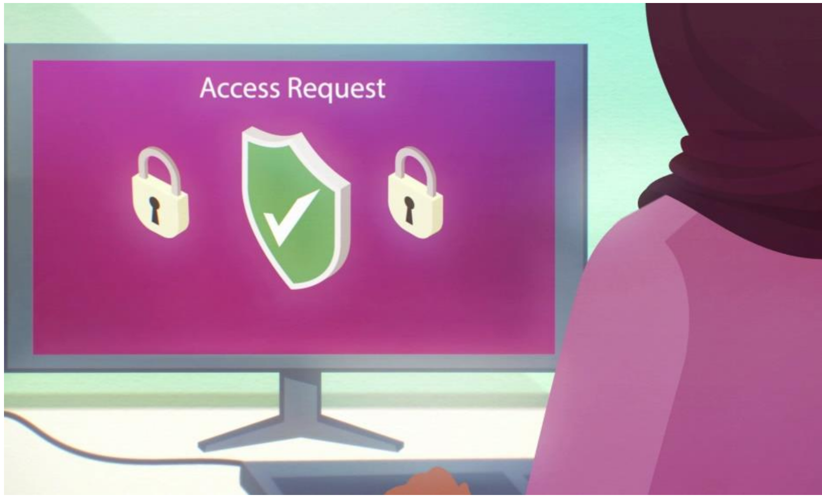
Consider that most people are unlikely to know how access to data works and how decisions are made

Most people want to know that:

- someone has responsibility for oversight about the purposes for which data can be used.
- there are strict controls on who can access patient data for research and planning, especially when it may be possible to identify someone from the data.

Remember to talk about the controls, including:

- Patient data uses can only be approved where there is potential for public benefit.
- The purpose must be approved before anyone can use the data. Try and provide information about who makes these decisions and how.
- That only the minimum amount of data necessary for the stated purpose will be used.
- It is an offence to re-identify someone from the data accessed.



Find out more about 1. How decisions are made including information about national organisations and independent groups who make decisions. 2. Patient journey animations describing stories of what happens to data and who sees it.

04

WHEN EXPLAINING WHAT SAFEGUARDS ARE IN PLACE TO PROTECT PATIENT DATA

Always mention how patient data is kept safe and secure to protect confidential information.

People will want reassurance that privacy is protected by:

- removing identifying information
- using an independent review process
- ensuring strict legal contracts are in place
- implementing robust IT security.

Consider the range of ways safeguarding takes place and use accessible language

Remove identifying information
The best way to protect someone's information is to remove details that identify a person and take further steps to 'anonymise' it. Anyone wanting to use patient data should only be given the minimum amount necessary.

Strict legal contracts
A legal contract must be signed before data can be transferred or accessed. This sets out strict rules about what an organisation can do with the data, when it must be deleted, and has clear restrictions on what is not allowed.

Independent review process
Requests to use patient data are often assessed by an independent review committee, who check that the reason for using the data is appropriate.

Robust data security standards
Data must be stored securely, with controlled access and robust IT systems to keep data safe.

Find out more about 1. The [safeguards](#) including a printable [safeguards explainer](#).
2. [Keeping patient data safe](#) (NHS Digital).

05

WHEN EXPLAINING THE RISKS OF USING PATIENT DATA

It is important to acknowledge that using patient data will never be totally risk-free. There must be robust measures in place to reduce the risks as much as possible.

There are also risks around not using data. Providing balanced and honest information allows people to weigh up the benefits and risks.

Patients’ concerns typically include:

- Loss of privacy, or information about their medical history being revealed to others.
- Loss of control if data is passed outside the NHS (including data being used to discriminate and for targeted marketing).
- The possibility of cyber attacks or hacking.

Risks around not sharing patient data include:

- NHS resources are not used as efficiently as possible and are potentially wasted.
- The safety and effectiveness of drugs and treatments are not monitored.
- Less is known about how to improve the health of some groups of patients.

Remember that:

What is an acceptable balance between benefit and risk will vary from person to person. People may accept greater risks if they are more likely to benefit directly.

Find out more about 1. Weighing up benefits and risk exploring in more detail concerns around data breaches, privacy, third party access and cybersecurity.

06

WHEN EXPLAINING IF PATIENT DATA BEING USED IS “PERSONAL DATA”

Be aware that people are often concerned about whether they could be identified from data.

When describing identifiability, it’s important to use words that are easy to understand while still being as accurate as possible.

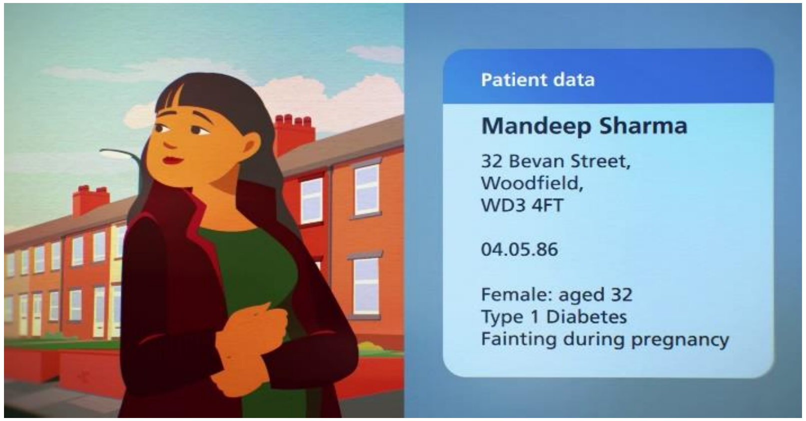
Be aware that the words used to describe whether a person is identifiable from data can be technical and complicated

It is important to clearly explain:

- whether data is “personal data” as defined by the law.
- what steps have been taken to remove identifiers.
- the risk of re-identification when different types of data are used.

When talking about whether data counts as “personal data”, it’s important to consider the environment in which data is being used, as well as what’s in the data itself. Depending on the risk of re-identification, different controls are needed.

Bear in mind that it may also be possible to work out who someone is by combining information from different sources — like joining together different pieces of a jigsaw puzzle.



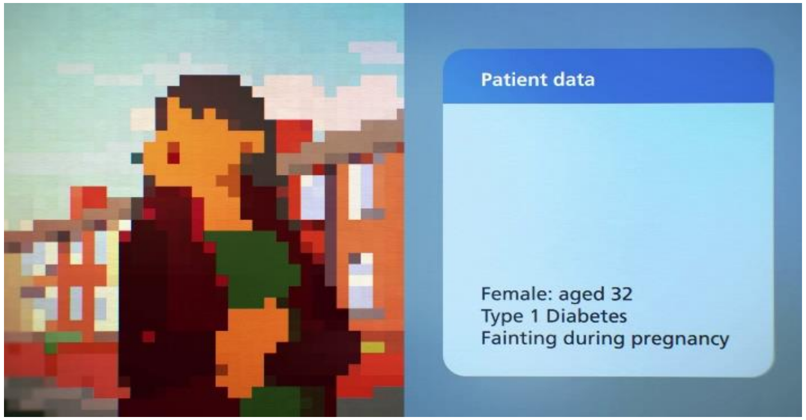
Patient data

Mandeep Sharma

32 Bevan Street,
Woodfield,
WD3 4FT

04.05.86

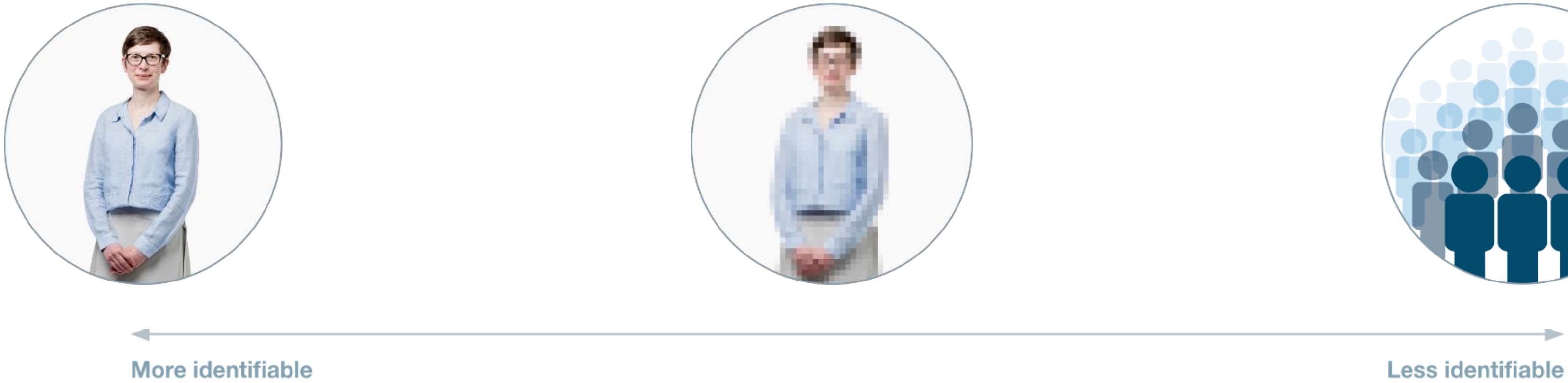
Female: aged 32
Type 1 Diabetes
Fainting during pregnancy



Patient data

Female: aged 32
Type 1 Diabetes
Fainting during pregnancy

Bear in mind that using images is a good way to help explain whether someone could be identified from data. It helps to think of identifiability as a spectrum



Personally identifiable information identifies a specific person.

Identifiers include: name, address, full postcode, date of birth or NHS number.

De-personalised information does not identify an individual, because identifiers have been removed or encrypted. However, the information is still about an individual and so needs to be handled with care.

It might, in theory, be possible to re-identify the individual if the data was not adequately protected, for example if it was combined with different sources of information.

“De-personalised” is not a legal term. It’s used here to help explain identifiability in simple terms.

Anonymous information is from many people combined together, so that it would not be possible to identify an individual from the data. It may be presented as general trends or statistics.

Information about small groups or people with rare conditions could potentially allow someone to be identified and so would not be considered anonymous.

Find out more about 1. How to talk about what anonymised means including a printable briefing and downloadable images. 2. The best words to use when talking about patient data.

07

WHEN EXPLAINING WHAT'S ALLOWED AND NOT ALLOWED

Remember that people want an idea of any 'red lines' and often don't know about strict rules protecting the use of patient data.

For example, it's important people are made aware:

- That patient data uses can only be approved where there is potential for public benefit.
- There are strict rules and where there are exceptions to those rules.

Consider that people may not know that there are strict rules on what's allowed and not allowed, and that there are can be exceptions too

Public benefit

People may not know that patient data can only be accessed if there is a potential for public benefit. This rule applies to everyone.

Consent

People may be familiar with the idea of providing explicit consent for research projects or trials, but in some cases consent is not required for data to be used. It's important to provide clear information about any exceptions that are allowed by law.

Marketing and insurance

When asked about the acceptability of patient data uses, people are often concerned that information about them will be used by marketing and insurance companies.

The NHS will never share personally identifiable data for marketing or insurance purposes, unless the individual gives the NHS permission to do so.

08

WHEN EXPLAINING WHAT CHOICES PEOPLE HAVE ABOUT HOW PATIENT DATA IS USED

It’s important to make people aware of their rights and choices in a way that is easy to understand and act upon.

Information should also be provided about:

- any impact their choice might have.
- how choices at local or regional level relate to choices that can be set at a national level.

People need accessible information to make an informed decision

If people do have a choice about how data about them is used, you should provide information on:

- The type of data the choice applies to. For example in England, the national data opt-out applies to the use of **confidential patient information** for research and planning purposes.
  Give examples where possible.
- Any exceptions when a person's choice won't be upheld. For example, if there are legal exceptions that could override a person's choice.
- The possible impact of their choices. For example, setting a national data opt-out in England will **not affect patients' individual care**. But having patient data about as many people as possible ensures that the NHS has the most complete information for making decisions about how to provide care.

**Be careful when describing what type of choice it is: opt-out, opt-in or consent.
Each type has a different legal or policy basis and public expectations.**

Only use the word **consent** if you explicitly ask people's permission in order to use the data.
Do not use 'consent' to refer to broad public acceptance or support for using patient data.

Remember there are different national policies in England, Scotland, Wales and Northern Ireland.

Find out more about 1. The national data opt-out including answers to common questions.
2. Why there's an opt-out rather than an opt-in or consent 3. The potential impact of the data opt-out

09

WHEN EXPLAINING WHY COMPANIES ACCESS PATIENT DATA

Remember there is low public awareness of companies being involved in providing care and research across and beyond the NHS.

People tend to support data being used for research, but they:

- are uncomfortable with companies accessing health information.
- have little understanding of why companies may access patient data.

Be open about why companies use data and provide examples where possible.

Be prepared that people may have lots of questions about companies using patient data

People have high trust in the NHS, but are less trusting of private companies and their **motivations** given their commercial interests. People may have heard about scandals involving private companies using health data.

Be ready to talk about:

- People’s concerns around whether the NHS sells patient data, and companies using patient data for marketing and insurance purposes.
- Why the NHS partners with companies (for example, for the expertise or technologies companies provide).
- The safeguards in place to protect privacy.

Remember to highlight:

- The NHS works in **partnership** with companies in many ways to deliver care and research across the NHS.
- What the **public benefit** is.
- That personally identifiable patient data can only be used if there is a **health benefit**.

Find out more about 1. How to talk about companies being able to access patient data including answers to common questions and examples. 2. Public attitudes to the use of patient data.

Understanding
Patient Data

How to find out more

UPD resources provide a starting point for better conversations around the use of patient data. We expect others to build and adapt them for their own needs, audiences and settings.

This guide does not cover the breadth of policy and engagement issues we work on. To find out more about what UPD is doing, latest news stories and guest blogs visit our news and subscribe to our **newsletter.**

This guide will be iterated in response to feedback, so please let us know if you find it useful or have suggestions for improvements.

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