

“Who is going to know about
this?”

Sharing information from Sexual
Health Services

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Acknowledgements
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Confidentiality in GUM

Special arrangements are made for confidentiality of GUM in recognition of:

- The stigmatisation of the need for sexual health care
- The interests of the Public Health to maximise appropriate uptake of services

NHS (VD) regulations 1974 and NHS Trusts and Primary Care Trusts (STI) directions 2000

- These provide that information regarding persons examined or treated for any sexually transmitted disease shall not be disclosed except:
 - “For the purpose of communicating that information to a medical practitioner, or to a person employed under the direction of a medical practitioner in connection with the treatment of persons suffering from such disease or the prevention of the spread thereof, and
 - For the purpose of such treatment and prevention”

Current position with GUM records

- Stand alone bespoke systems
- Not connected to hospital systems
- Many have lab links
- Tests and prescriptions ordered under unique GUM identifier and d.o.b.

Sexual Health Care Outside GUM

- Sexual health information is also held in the records of:
 - GPs
 - community contraceptive services
 - abortion services
 - sexual dysfunction services
- Should the confidentiality requirements judged necessary and sufficient for GU be enacted in any other settings?

Management of HIV patients within GUM

- Most HIV care is OPD based with occasional in-patient episodes
- Many clinics still manage OP HIV within GUM case note system
- But for Infectious Disease services and some GUM services HIV patients being managed within mainstream hospital case notes or EPR system

With electronic records we need to ensure

- Confidentiality to enable initial access to testing and treatment
- Confidentiality to facilitate clinical consultations
- Confidentiality as defined in the Care Records Guarantee

We need to share

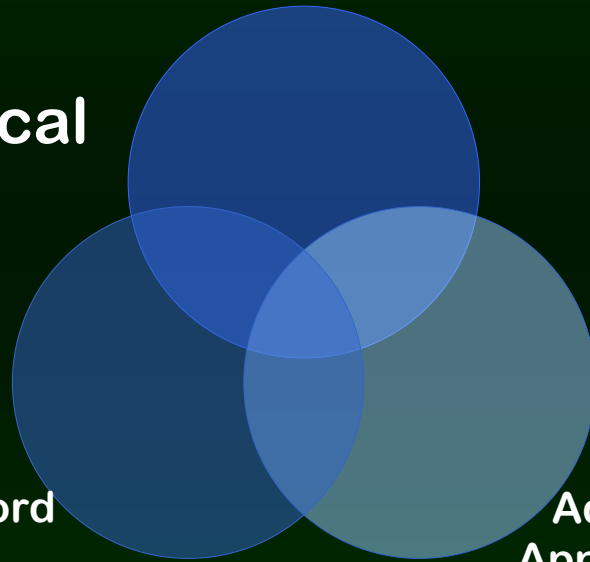
Clinical notes
Investigations, results, treatment

Within the clinical
department

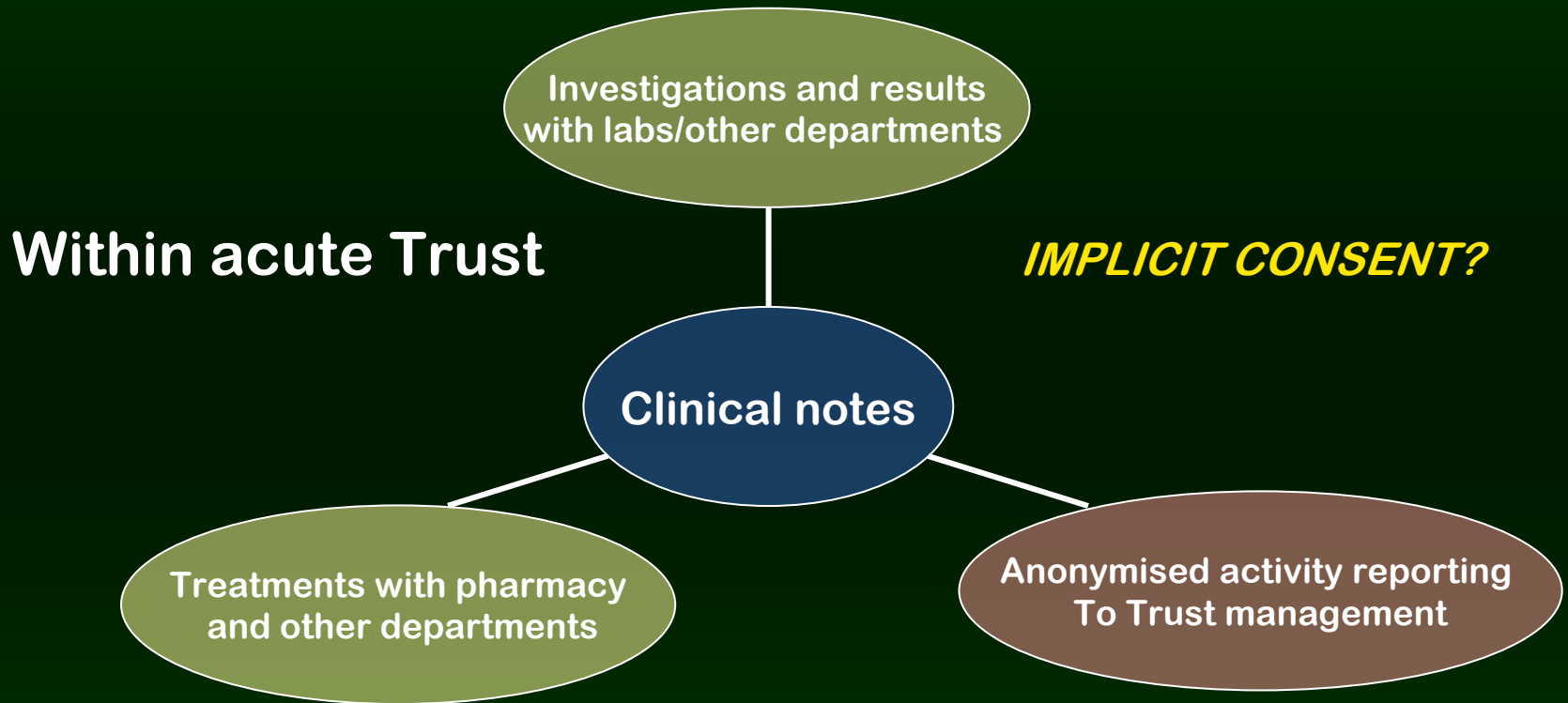
IMPLICIT CONSENT?

Administrative record
Demographics

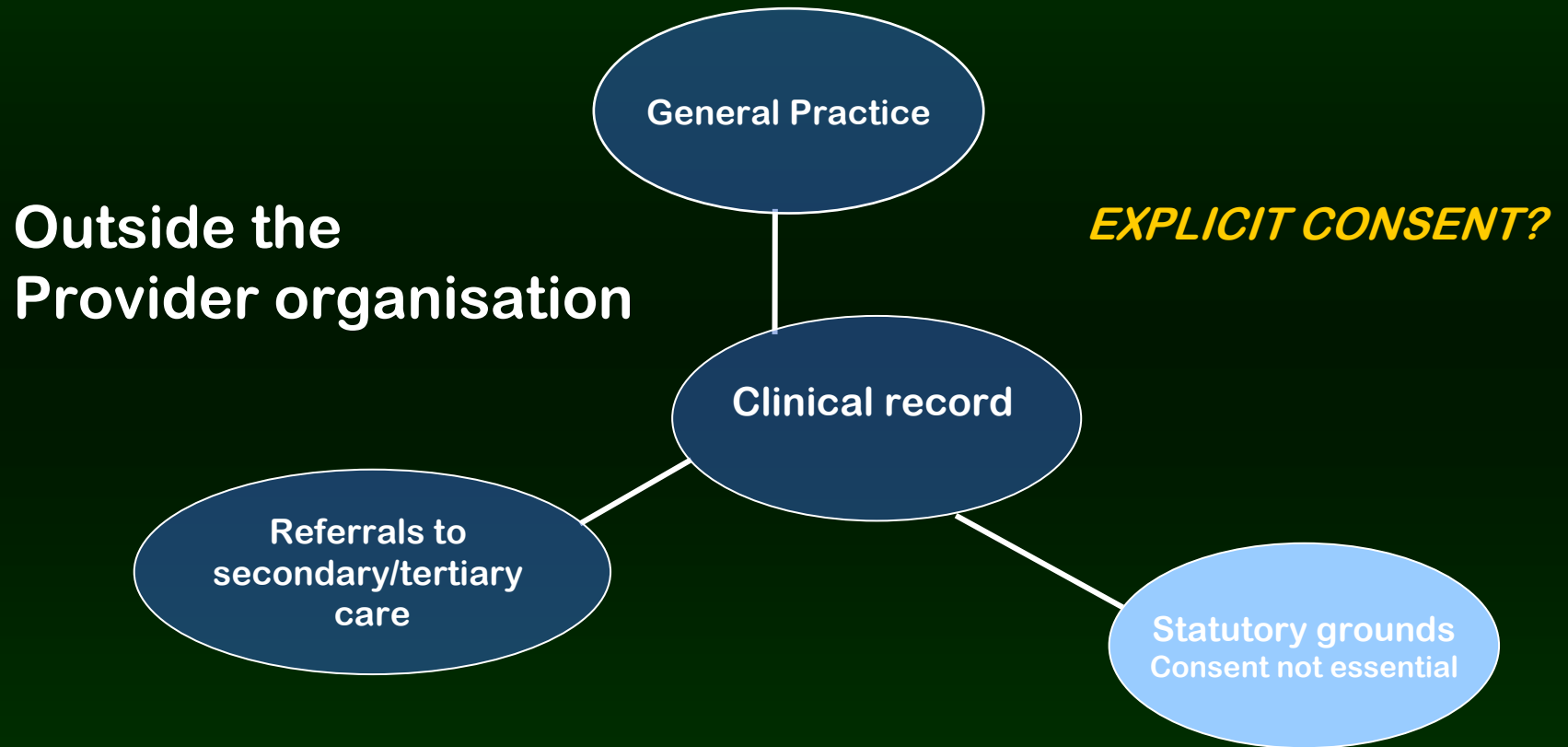
Administrative record
Appointments and letters



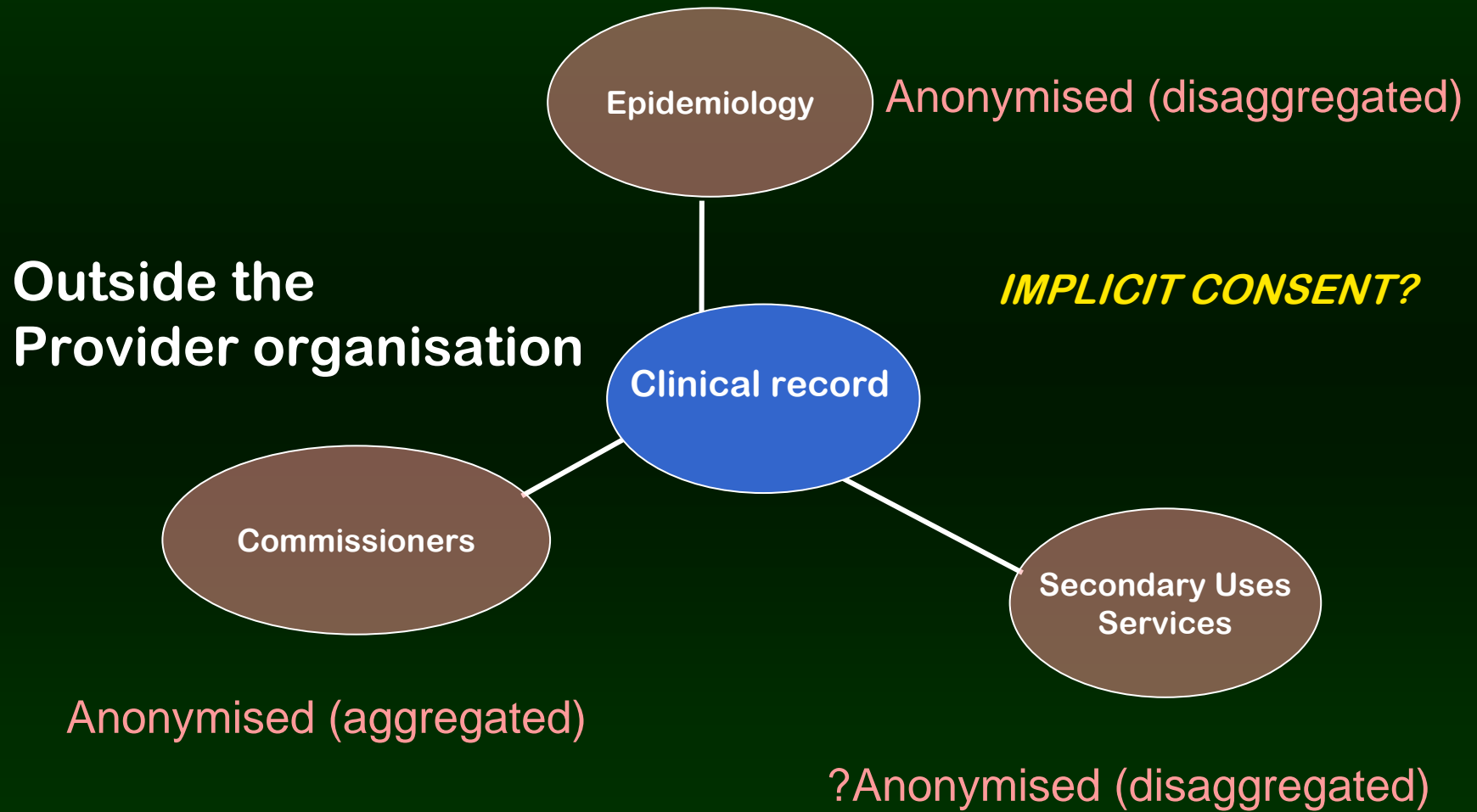
We need to share



We need to share



We need to share



Consent (and dissent?) to information sharing

- Who decides?
 - Patient
 - Clinician
 - Patient and clinician at consultation
 - NHS Connecting for Health
- How is consent obtained?
- How is consent recorded/changed?
- What should the default position be e.g. no sharing, sharing within the Trust

Key unresolved questions

- What to do about patient requests for 'NO information sharing' beyond clinical team?
- What to do about patients who tell us they are presenting with false name/address?
- NHS number – how might we work with/without it?

HIV case records

- Is it clinically safe to maintain separate case notes for the same condition?
- Would HIV patients' confidentiality be compromised with unified case records?
- How do we cater for HIV+ patients who choose to remain anonymous?
- Should HIV related information be withheld from other clinicians who have a legitimate relationship with the patient?

CfH and Sexual Health Conference

March 2007

- 120 delegates
 - Clinicians (few), managers, patient reps, IT specialists
- Plenary presentations
 - GUM/RSH, FPA, Brook, patient rep, CfH
- Strong audience participation to obtain views on
 - Sharing information in GUM
 - Anonymity
 - Proposed CfH IG controls
- Generally a positive reaction to the IG controls proposed by CfH

Conference March 2007

Results: Sharing

- Majority thought that all sharing should be possible WITH patient consent
- Sharing should be decided by the clinician and patient together (77%) or patient alone (23%)
- The default should be 'no sharing' (69%) or sharing GUM to GUM only (15%)

Conference March 2007

Results: Anonymity

- 100% thought that any system MUST be able to allow anonymity of care
 - no link to NHS number
- Many also felt that linkage to the NHS number and therefore the patients general health care record should be possible
- The default should be either
 - total anonymity (50%) or
 - record linkage using unique sexual health ID (24%)

Ongoing Work

- Formation of small working group
- Over to Jackie Sherrard