The wait….
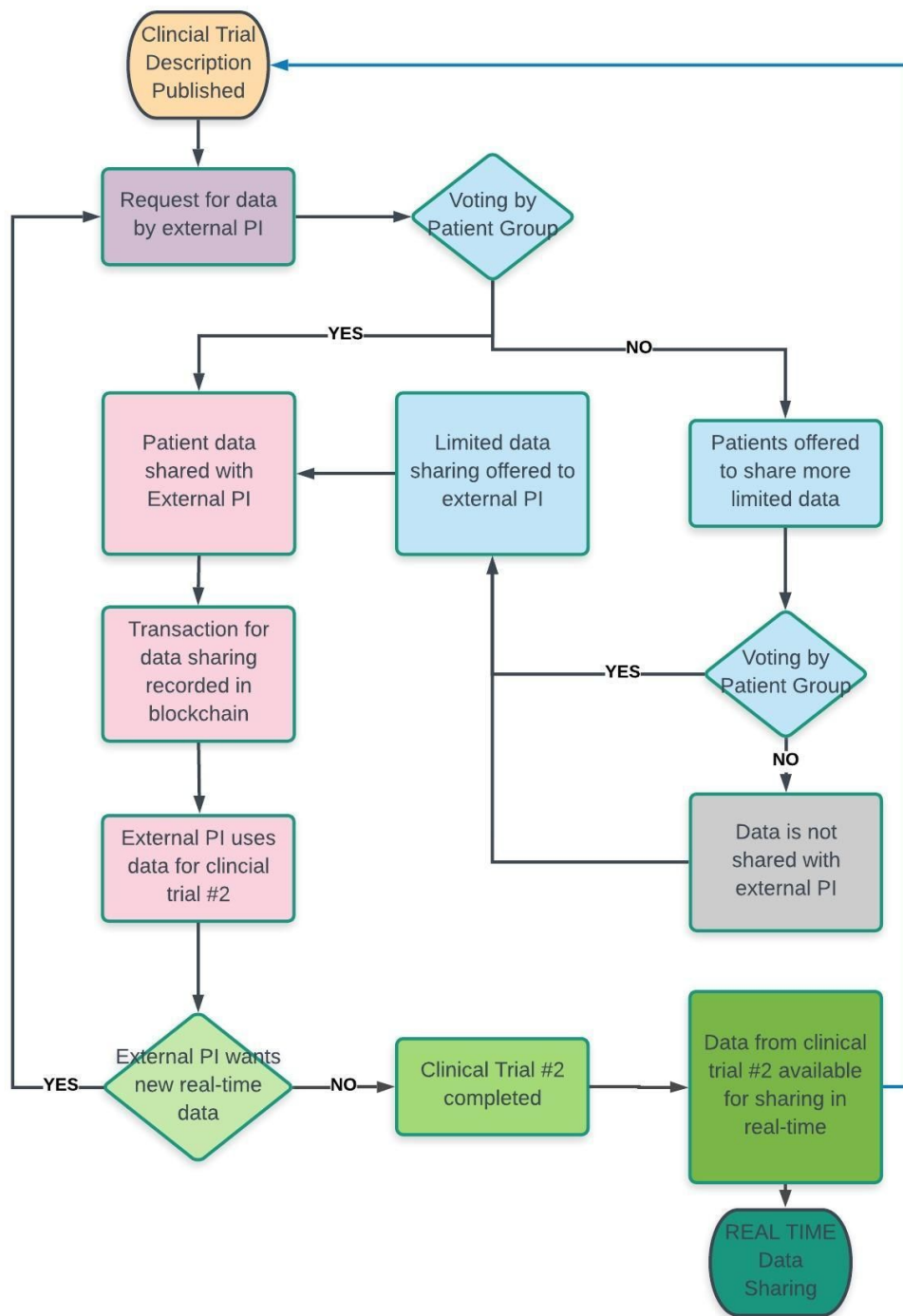
 Those suffering from rare diseases have a time-dependent need for treatment

 Data-sharing Time: Length of Trial + Peer Review process for output

 Other trials using the same experimental for other purposes

Block Chain

✔ Transparency

✔ Data encryption with keys

✔ Utility: Contracts (e.g. Ethereum) and Quorum Voting (e.g. Algorand)

✔ Real-time tracking of data with consensus

SPARSITY FLOW CHART

REAL TIME TRIAL DATA SHARING

Clincial Trial Description Published

Request for data by external PI

Voting by Patient Group

YES — NO

Patient data shared with External PI

Limited data sharing offered to external PI

Patients offered to share more limited data

Transaction for data sharing recorded in blockchain

Voting by Patient Group

YES — NO

External PI uses data for clincial trial #2

Data is not shared with external PI

External PI wants new real-time data

YES — NO

Clinical Trial #2 completed

Data from clinical trial #2 available for sharing in real-time
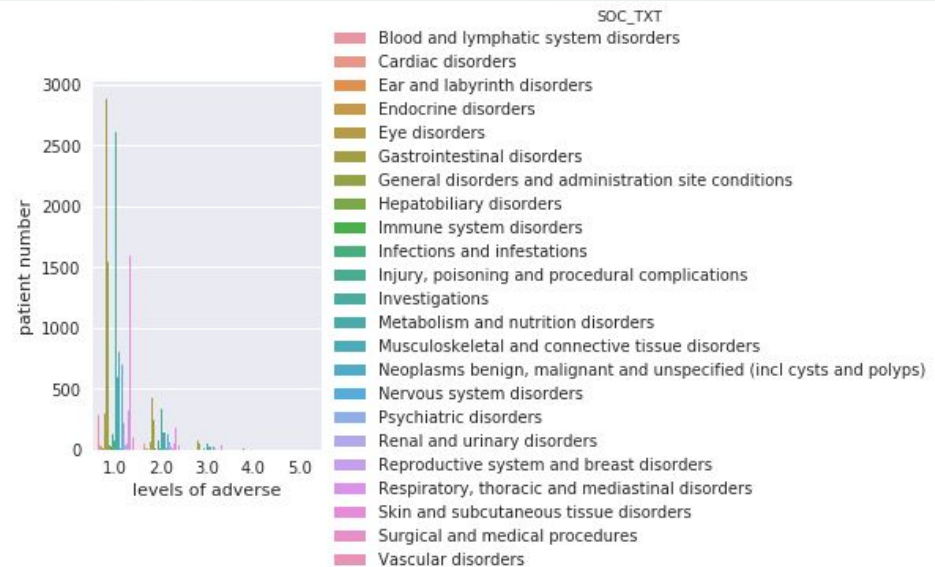
REAL TIME Data Sharing

Sparsity Platform

```python
def new_block(self, proof, previous_hash, voting_doc, voting_pat):
    """

    define new block here

    :param proof: The proof given by the Proof of Work algorithm
    :param previous_hash: Hash of previous Block
    :return: New Block
    """

    # voting is the value that if the patients willing to share the code
    if voting_doc or voting_pat == 0:
        return Null
    else:
        block = {
            'index': len(self.chain) + 1,
            'timestamp': time(),
            'transactions': self.current_transactions,
            'proof': proof,
            'previous_hash': previous_hash or self.hash(self.chain[-1]),
        }

        # Reset the current list of transactions
        self.current_transactions = []

        self.chain.append(block)
        return block
```


SOC_TXT
- Blood and lymphatic system disorders
- Cardiac disorders
- Ear and labyrinth disorders
- Endocrine disorders
- Eye disorders
- Gastrointestinal disorders
- General disorders and administration site conditions
- Hepatobiliary disorders
- Immune system disorders
- Infections and infestations
- Injury, poisoning and procedural complications
- Investigations
- Metabolism and nutrition disorders
- Musculoskeletal and connective tissue disorders
- Neoplasms benign, malignant and unspecified (incl cysts and polyps)
- Nervous system disorders
- Psychiatric disorders
- Renal and urinary disorders
- Reproductive system and breast disorders
- Respiratory, thoracic and mediastinal disorders
- Skin and subcutaneous tissue disorders
- Surgical and medical procedures
- Vascular disorders

	SOC_TXT	AEVGRD1C	MASK_ID
0	Blood and lymphatic system disorders	1.0	279
1	Blood and lymphatic system disorders	2.0	51
2	Blood and lymphatic system disorders	3.0	5
3	Blood and lymphatic system disorders	4.0	2
4	Cardiac disorders	1.0	41
5	Cardiac disorders	2.0	10
6	Cardiac disorders	3.0	3
7	Ear and labyrinth disorders	1.0	25
8	Ear and labyrinth disorders	2.0	12
9	Ear and labyrinth disorders	3.0	2

Considerations

- Who owns the research? Publications…
- Pharmaceutical companies role
- FDA: Accelerated Approvals…Right to Try…Orphan Drug Designations…Medical Devices…

Future Directions

- Easier and faster data sharing with FDA
- Incorporate data with HIPPA Compliant EMR (e.g. Epic)
- Novel investigational collaborations
- Patient autonomy in digital era
- Post-market surveillance

Thank you

Patient Consensus

New Drug Discoveries